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**Tuberculosis, HIV, Food Insecurity, and Poverty in rural Zambia:
An ethnographic account of the Southern province**

by

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**A dissertation submitted for the degree of
MASTERS OF PHILOSOPHY
in the Department of Social Anthropology
Faculty of the Humanities
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PLAGIARISM DECLARATION

I, Mutale Chileshe, declare that the material in this thesis is based on my original work (except where acknowledgments indicate otherwise), and has not, in whole or in part been submitted towards another degree, at this University or elsewhere. The University is empowered to reproduce either the whole or any portion of the contents for purposes of research.

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ABSTRACT

Tuberculosis (TB) remains one of the most devastating diseases in the world, affecting people of all ages across the globe, and is responsible for 11% - 60% of the total deaths of people living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in Sub Saharan Africa. Although tuberculosis is a disease that is found throughout the world, the overwhelming majority of cases are found among the poor. Poor and socially excluded people face greater exposure to many health threats and, when they fall sick, they are far less likely to receive adequate care.

Addressing the emergent phenomena of rural tuberculosis and the advanced HIV epidemic, this thesis explores issues of economic crisis, food security and emotional burden from the perspective of rural people impacted by TB and HIV/AIDS. The main argument in this thesis is that the poor population has a limited capacity to cope with the trajectory of TB illness in the context of food insecurity and at this stage of the HIV epidemic, without external welfare support.

The thesis is based on fieldwork conducted in Pemba/Batoka in the Southern part of Zambia between September 2006 and July 2007. The core approach of fieldwork was case studies of nine people (four women and five men) who were suffering from TB, and their households; and a comparative sample of seven households that did not have a TB patient. The participatory methods included timelines, seasonal calendars, observation and semi-structured interviews. The main aim of all methods was to find out how the nine TB patients experienced life in a wider social context, the problems they faced within their households in terms of food security and accessing both TB and HIV treatment.

From their experiences, it was reported that no TB patient households were in receipt of food aid. None of the TB households was ever visited by home-based care or received any material assistance from organisations or government. The care of TB patients fell on female kin – mainly mothers - with limited assistance from the extended family and

neighbours.

Due to illness, a drop in agricultural production was recorded in 6 out of 8 TB patient households (2006/7 compared to 2005/6 farming season) while non-affected households recorded an increase. Both TB medication and Anti-Retroviral Treatment (ART) are thought to increase the 'hunger' of TB patients and should, it is believed, be taken with food. Consequently, TB patient households spent more money on food, while comparative families spent more on farm inputs like seed and fertiliser.

The study also shows that access to care in rural areas can be very costly. Accessing ART in the rural area involved repeated visits to the hospital and substantial costs. Due to these accumulated costs, some participants and their households were tipped into deeper poverty. In addition, TB tipped households into emotional turmoil - precipitating divorce, splitting up households and straining key family relationships. From their experiences, the study reveals that it is indeed very difficult for the poor to cope with TB and HIV without external support.

DEDICATION

I dedicate this study to my Father, **Sylvester Bwalya Chileshe**, for all his support and encouragement. I want to thank you dad for teaching me that education; hard work, perseverance and love for the less fortunate are important in one's life. You have always been my inspiration.

Above all, I give praise to God, who never planned that any person be poor on earth.

University of Cape Town

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¹ ZAMBART - a London School of Hygiene and Tropical Medicine and University of Zambia collaborative research project of 18 years standing. Its main focus is research on TB and HIV related issues.

² Zambia and South Africa Tuberculosis and AIDS Reduction Study is a seven year trial (2004 to 2011) that aims to measure the effectiveness of three different approaches to reduce TB in poor communities with high HIV prevalence. The study is being carried out by the ZAMBART Project, the London School of Hygiene and Tropical Medicine and the Desmond Tutu TB Centre, University of Stellenbosch, with support from John Hopkins, under the CREATE Consortium.

interpreting and transcribing of data. She was also a friend and a sister when I needed one.

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A special thank you goes to Regional Network on HIV/AIDS, Rural Livelihoods and Food Security³ (RENEWAL) for sponsoring my Masters studies at the University of Cape Town

³ Regional Network on HIV/AIDS, Rural Livelihoods and Food Security (RENEWAL) is a regional network-of-networks to generate priorities for research and action on HIV/AIDS and food security, and strengthen in-country capacity to respond to the epidemic.

and for making this study possible.

I particularly want to thank the ‘greatest surveyor in the whole world’ - my father - Sylvester Chileshe, for the lovely map of Zambia and for his calculations of the distances between the towns of Southern Province. To Mary .N. Chileshe, I thought of you throughout my study and I know your spirit is always with me.

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To them I say, “I am because we are.”

GLOSSARY OF TERMS

AIDS	Acquired Immune Deficiency Syndrome
ARVs	Anti-Retroviral Drugs
<i>Butala</i>	Grain bin
DOTS	Directly Observed Treatment Short Course
GDP	Gross Domestic Product
FAO	Food and Agriculture Organization
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
NGO	Non-Governmental Organization
NHC	Neighbourhood Health Committee
<i>Insima</i>	Thick porridge made from maize meal
Piecework	Forms of casual or informal labour
PLWH	People living with HIV
RHC	Rural Health Centre
STD	Sexually Transmitted Disease
TB	Tuberculosis
UNDP	United Nations Development Programme
UNICEF	United Nations International Children Emergency Fund
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WFP	World Food Program

Note: K4000 is equivalent to \$1US and R7.70⁴

⁴ Source: <http://www.xe.com/ucc/convert.cgi> [2008, January 19]

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

It was a lovely day on a hot September morning. Driving along a dusty path with trees and wild grasses on both sides, I watched the birds fly from tree to tree. For almost half an hour there was no sign of human life. Villages in Pemba and Batoka are situated far from the main road, the Lusaka- Livingstone Road. After thirty minutes, we saw four women and two young girls around a hand pump; wrapped in old looking and worn out *chitenges* - women's waist cloths worn over a dress or shirt - they were chatting and laughing. They had many 2litre and 20litre containers for drawing water. Like most rural residents, people of Pemba and Batoka use pit latrines or the bush; and their homes have neither electricity nor running water.

We drove a little further and, from afar, we saw huts - round wattle and daub structures, with thatched roofs, resting on a centre pole - scattered in the bushes with a few children playing and very thin dogs lying around the compound. A compound is composed of several huts. Upon seeing the huts, I began to get excited - at last, we were approaching Mary's compound. Mary lived 32km from where I lived, with her son who had TB, a man, aged 30 named Rocky. Mary's family was the first to join my study and it explained the excitement and the anxiety I felt as we drove to their home. I had a sleepless night trying to go over what I would ask them and how I would explain the study. I anticipated that some anxiety and resentment may arise due to this being a purely research study with no interventions or incentives, like food aid.

My first impression as I approached Mary's compound was that it looked like a comfortable home. The compound, which included three huts and one house⁵, was well

⁵A house is made of burnt bricks and has an iron roofing sheet. The typical compound in Pemba has huts (see section on Ethnographic Background).

maintained. It had lot of fruit trees - mango, berry, lemon, and pawpaw. However, when I saw Rocky and his two children, his nephew, his wife, and his mother; this impression changed and my excitement slowly diminished. Rocky was lying under a tree and looked so lifeless, I thought he was dead. He was very thin and looked like he had not eaten anything that morning because his lips were so dry. He was breathing heavily and looked disturbed. I opted not to talk to him because I assumed he was too ill to sustain a conversation from a highly-expectant anthropologist-in-the-making.

I spoke with Mary, who initially welcomed me, and in the first few minutes of our conversation she started crying as she narrated her family's ordeals. Mary seemed appreciative of having a visitor who had come to talk to her exclusively - so much so that her tears possibly reflected both her sorrow and relief at having a chance to speak. At the time of my visit, Mary had been excommunicated from her church, leaving her family feeling alone and sad. Due to her frequent visits to traditional healers, Mary told me that some of her church members did not want anything to do with her and her family; hence barring her from entering the church. During her story, Rocky suddenly showed some life by stretching to sit up. He stared at me, trying to smile, but even this appeared painful given his condition.

I had to say something to Rocky; I would not just sit there and stare at him, so I asked, "Do your friends come to chat with you?" He did not answer but started to cry, after a few minutes he replied, *"None of my friends have visited me, they fear that I might infect them."* He also started crying when he talked about how he was scared that he would die before his children grew up.

I thought to myself, "I am upsetting this man. Maybe I should end this conversation." So I quickly apologised and asked him if it was alright for me to visit him another day. Then he replied, *"Please do stay. We never have visitors at this home, people are scared of getting infected and I am happy that I can talk to someone."* The pleading in his eyes made me stay and I was very happy that, although I was not offering any food or money to these people, I was giving them something - friendship. Of course I would not be a friend *per se*

because I was there to research - I had to distance myself (Scheper-Hughes 1992). The social worker in me knew I had to empathise, but not to sympathise.

Therefore, although my fieldwork was emotionally and physically taxing since I was dealing with people who were sick and poor and who cried many times during conversations, I had to sustain the excitement that I had once felt on my way to meeting Rocky's household. Because, if they were my informants, I was very much their intermediary (Scheper-Hughes 1992), an intermediary who was going to write about their suffering with the hope that policymakers or welfare institutions would hear the cry of people like Rocky. Through writing I knew I would draw others (colleagues, scholars, governments, NGOs and friends) and make them part to the act of witnessing (ibid: 1992).

In view of the above, this thesis is based on fieldwork conducted in the Southern part of Zambia between September 2006 and July 2007. The focus of the thesis is the life of the poor affected by TB. Farmer (1999:185) rightly states, "Those who experience tuberculosis as ongoing concerns are the world's poor, whose voices have systematically been silenced." This thesis explores issues of economic crisis, food security and emotional burdens from the perspective of poor households impacted by TB and HIV. The study looks at how rural households affected by TB experience life within the household and argues that poor rural households have a limited capacity to cope with the trajectory of TB illness in the context of food insecurity and at this stage of the HIV epidemic, without external welfare support. In a country like Zambia, 86% of the population is estimated to be living in poverty, of which approximately 72% is living on less than a dollar a day (World Bank 2001). In addition, the vast majority (62%) of these poor are living in rural areas (World Bank 2007); therefore it becomes very important to look at the lives of the poor.

1.2 An overview of Zambia

“Poverty is not natural; no child is born to be poor and destined to lead an insecure life. Neither does poverty descend from the skies like rain or hail; it is rather the consequences of a more fundamental cause.” (Akokpari 2007: 18)

Zambia is among one of the poorest nations in the world (Loewenson and Whiteside 2001), but this had not always been the case. After Independence in 1964 and a few years later, Zambia had one of the highest GDPs in Africa (Ferguson 1999). The economy was thriving in a large part because copper, the country's main export, was doing well on the international market. This economic boom did not last long. In the 1970s the country was faced with two economic crises that affected its prosperity - the rise in oil prices and the fall in the copper prices on the world market (see Mwanza et al. 1992). The failing economy pushed Zambia into debt, eventually creating a debt crisis that further entrenched poverty in the 1990s (Rakner 2003; ibid 1992).

Facing a growing debt crisis, the Zambian government accepted help from the International Monetary Fund and the World Bank. In exchange, the government implemented structural adjustment programmes (SAP). Unfortunately, SAP did not produce the anticipated economic growth but instead contributed to an increase in unemployment, prostitution, crime and the failure of government to provide social services (Mwansa et al. 1992).

In rural areas, livelihood services deteriorated due to expensive and poor distribution of fertiliser and the non-existence of an adequate crop marketing system. For instance, Southern Province (where I conducted my fieldwork) was known for its ideal farming conditions (Moomba 1989) until the time that agriculture policies changed. Firstly, subsidies for fertilisers and farm implements were phased out. Secondly, according to Johan Pottier, “policies that were made overlooked the knowledge of villagers who knew

how to carry out diverse kind of farming” (1999:170). Apart from these policies, droughts and cattle diseases began to plague the area, thus deepening the poverty situation (See Bangwe 1997; Chipungu 1987; Foster 1993; Moomba 1989; Waller 1997). In addition to the poverty highlighted above, the country also has to deal with the prevalence of HIV infection.

When AIDS emerged in the 1980s, the Ministry of Health was ill equipped to deal with a public health crisis, particularly in the face of economic declines in the 1970s and the structural reforms of the 1980s. With AIDS came a subsequent rise in infectious diseases such as TB.

Today, Zambia has one of the highest incidences of tuberculosis in the world. Available medical statistics indicate that tuberculosis now accounts for one of every six adult deaths in Zambian hospitals. Whereas at Independence Zambia had a TB prevalence rate of approximately 100 cases per 100,000 persons, the situation has worsened over the years. In 2004 alone, the case rate of TB was estimated at 450 cases per 100,000. In 2005, it was approaching 500 cases per 100,000 and the mortality rate is estimated at 88.7 per 100,000 persons. [<http://allafrica.com>].

TB may push already poor households into deeper poverty and vulnerability due to loss of income coupled with increased expenditure on treatment, food consumption and care (Ahlburg 2000; Kamolrantanakul et al. 1999; Ogden 1999; Rajewsari 1999). Also TB-food security issues stretch from the onset of illness, to diagnosis, to cure or death, and revolve around the vicious cycle of TB and poverty (see Farmer 1999, 2000; Killewo 2002). Add to this the wider contexts of HIV and Zambia’s economic downturn; it is understandable that poor households are struggling, and sometimes failing, to cope with TB.

1.3 Ethnographic background

I conducted my research in the Southern part of Zambia, in Choma District⁶. The study area covered Batoka, Kasiya, Muzoka and Pemba. Batoka, Muzoka and Pemba lie on the Lusaka-Livingstone road and are thoroughfares to other towns. Batoka is almost the midway point between Livingstone (222km) and Lusaka (251km). Batoka and Pemba are about 35km apart while in-between Batoka and Pemba is Muzoka. 7km from Pemba on the dust gravel road to the west is Kasiya (See Fig.1). The study site (hereafter Pemba/Batoka) has an estimated population of 33520 (Kasiya 6981, Muzoka 7400, Pemba 7260 and Batoka 11879)⁷.

The Tonga people inhabit the area⁸ and the language mainly spoken in Pemba/Batoka is Tonga. There are other ethnic groups like Lozi, Ngoni, Bemba and Toka-leya that are found in the site but these are in the minority. According to Elizabeth Colson, an anthropologist who has done longitudinal studies for over 40 years in the valley Tonga, “Tonga is a word of unknown and possibly foreign origin. Today Tonga is a common name accepted by all people” (1958a: 7). Tonga language is called *citonga* while *mutonga* is for a single person and *batonga* for several people. Colson (1958a:7) writes, “The Tonga have no recorded history that goes back prior to 1853, when Livingstone first encountered them on his trek. Nor do they have any traditional history of their own which would allow us some time perspective on the development of their society.” Therefore, the Tonga people have no legends of migration, nor any historical accounts written about them before Colson embarked on her studies.

Pemba/Batoka is predominantly a rural area with villages (mud, brick and thatched houses) with traditional leadership (headmen, chiefs). In the site 97% of households are full-time

⁶ Choma is one of the eleven districts in Southern Province; others are Gwembe, Itezhi-tezhi, Kalomo, Kazungula, Livingstone, Mazabuka, Monze, Namwala, Siavonga and Sinazongwe.

⁷ Information about population was obtained from the clinics. They have records from the last census.

⁸ The Tonga consist of all the tribes of Southern Province in addition to Lenje from Central Province and also Soli and Gowa tribes from Lusaka (CSO 2004a).

farmers and less than 0.5% of farmers own more than 100 ha. The majority of farmers also keep livestock, mainly cattle, but also goats, sheep pigs and chickens. Agricultural constraints include recurrent droughts, floods in low lying areas, poor availability of improved seeds, poor rural infrastructure, livestock disease and poor access to government services (FASAZ 2003). Other economic options include petty trading; limited formal jobs in railway, civil service, and on commercial farms; beer brewing; and sex work survival strategies for women.

The Tonga people are matrilineal in lineage and inheritance. They have an extended family system built on polygamous marriages. Polygamy is a symbol of status and is a feature common in the villages but not in the towns. In this setting, a household is a residential unit created by marriage of people of different matrilineal groups (see Colson 1958a: 99). The huts are arranged to suit this family structure.

The husband and other older members of households (usually men) build huts for women and children. In a polygamous marriage, each of the wives has a hut and the men move from hut to hut. Other than huts, compounds in the site are composed of a central cooking place (*chikuta*), a central maize barn (*butala*), groundnut granaries (*kabbule*), chicken run (*caanda chankuku*), cow kraal (*ciba can'gombe*), goat kraal (*caanda champongo*) (see fig.2, 3, 4 and 5). The last two are typical of wealthy households. Of particular importance in my study site are cattle⁹. They play a very special role in defining one's sense of wellbeing; They also have a role to play in one's success in the farming system and are a defining factor in the local conception of wealth. For a Tonga man and woman to be wealthy (*kuvuba*) or to have property (*lubono*) literally means to have a lot of cattle (Milimo et al. 1994:10; Scudder 1962:161). Beyond the compounds lie the fields for crop cultivation. Vegetable gardens can be found near streams.

⁹ For more information on the role of cattle among the Tonga see Colson (1951: 10 - 46).

Figure 1: Map of Zambia

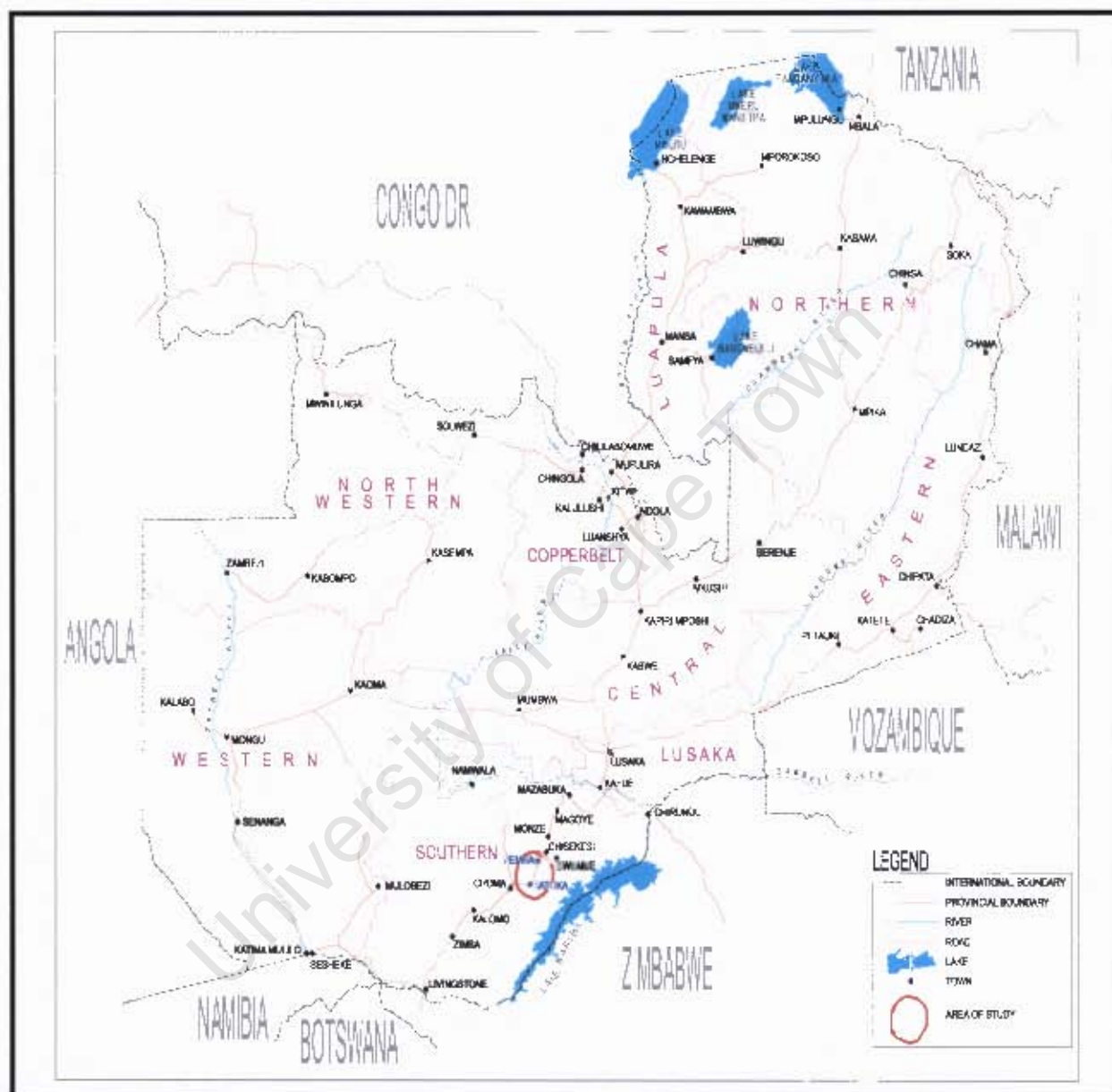


Figure 4: *cuanda champongo*- a goat kraal



Figure 5: a *butala*-maize bin and a rail for hanging fresh maize cobs



1.4 Why Anthropology?

I first came into contact with an anthropologist, Virginia Bond, when I started working with a project called ZAMSTAR¹⁰. Through my contact with Dr. Bond I became familiar with anthropology scholars who worked in Zambia - Audrey Richards, Henrietta Moore, Megan Vaughan and Thayer Scudder. Through my association with Dr Bond, I also came to meet and was inspired by Deborah Crooks, Elizabeth Colson, Lisa Cliggett, Pauline Peters and Sandra Wallman. Under the supervision of Dr. Bond I worked closely with people suffering from TB and their families and, though I did not know it at that time, I was utilising ethnographic research methods in the communities we visited.

Though falling within the wider ZAMSTAR framework, this study was funded separately by the International Food Policy Research Institute (IFPRI) and had separate objectives, methods, outcomes and a separate timeframe. The study is one of a group of studies funded by IFPRI in the Sub-Saharan Africa region under a programme called “RENEWAL”¹¹. The Social Science Investigator (Virginia Bond), ZAMSTAR, wrote the original proposal to IFPRI.

The study was conducted in Zambia and South Africa and was regarded as an opportunity for two African Social Scientists, from South Africa and Zambia, to further their careers by having two distinct field sites and contexts. I was offered this chance. My South African counterpart conducted her research in Mbekweni, Paarl District, Western Cape. Although

¹⁰ The Zambia and South Africa Tuberculosis and AIDS Reduction study (ZAMSTAR) - carried out by ZAMBART (a London School of Hygiene and Tropical Medicine and University of Zambia collaborative research project of 18 years standing) and the University of Stellenbosch, with support from STOP TB and John Hopkins, under the CREATE Consortium. ZAMSTAR has 16 sites in Zambia and eight in South Africa.

¹¹RENEWAL: Regional Network on HIV/AIDS, Rural Livelihoods and Food Security. It is a regional network-of-networks to generate priorities for research and action on HIV/AIDS and food security, and strengthen in-country capacity to respond to the epidemic.

we had similar research questions and research designs, her dissertation is independent because we conducted our work in two different countries and settings.

Therefore, this thesis draws inspiration from close to two years of my personal involvement and work with TB patients in the ZAMSTAR Project. After observing the poverty levels in the communities and households with TB patients, I started examining and interrogating how these households were coping amidst high poverty levels and the declining food security situation. With the help of the project and my supervisor, I enrolled at the University of Cape Town (UCT) where I attended an ethnography course and developed my M.A. proposal. I conducted fieldwork in Pemba/Batoka for ten months, from September 2006 to July 2007.

1.4.1 Link between social work and anthropology

The combination of social work and anthropology was a great inspiration for me as I pursued this study. Social workers have a duty to help people function in the best way they can in their environment, deal with their relationships, and solve personal and family problems. In particular, public health social workers provide persons, families, or vulnerable populations with the psychosocial support needed to cope with chronic, acute, or terminal illnesses, such as cancer or AIDS. In addition, they advocate for policy change so that individuals and families can have a better life.

Anthropology, on the other hand, comes from the Greek word meaning “the study of man”; and has been called “the most scientific of the humanities and the most humane of the sciences” (Helman 2007). Although Anthropology is often solely recognised as the study of “remote cultures that seem, at first glance, to have little to do with the problems of the contemporary world” (Nanda 1991: 437), like social workers, “anthropologists also put their knowledge to work to solve problems” (ibid 1991). Thus with both social work and anthropology I will be in a better position to help people with their problems.

Using my skills of social work, I will learn about people's problems and, from the perspective of the affected, I will be in a position to identify the most pressing struggles. However, as an anthropologist, my duties can go further than that, as I will be uniquely qualified due to my ethnographic training (ibid 437) - not only to gather data from groups but also to give a detailed description of their lives, since I am privileged to have lived some part of their lives with them (Scheper-Hughes 1992) - and thus understand their situation to a greater extent.

Through writing about the experiences of these people and having their voices heard through my narrative, I hope that one day someone will be able to do something about the rural poor of Pemba/Batoka. The main outcomes of the study will be the thesis and academic papers. The findings will be disseminated to the Pemba community and to the relevant policymakers. This will be done through community dissemination, publications and presentations at international conferences¹² and other forums.

1.5 Recruitment of participants

ZAMSTAR (the clinical control trial) provided a frame for a sampling strategy for this study. There are 16 ZAMSTAR project sites in Zambia and each site has a team at community level. In Pemba/Batoka the project team is responsible for implementing the enhancement of TB and HIV services and interventions such as household counselling within the government health system for a period of three years (mid 2006 to mid 2009). Newly diagnosed TB patient households were identified through the government health centres.

Two types of households were recruited to allow for a better understanding of the impact of TB: Households where a person was newly diagnosed with TB and households where

¹² So far the study has been presented in Rio de Janeiro at a research consortium meeting; and in Cape Town during the 38th Union World Conference on Lung Disease 2007

there was no patient.

1.5.1 Households with a patient

For this study, eight homes that had a TB patient were recruited. From the eight homes recruited, one of the homes had two TB patients, taking the total number of TB patients to nine. Of the nine, five were men and four were women. In the course of the study I learnt that seven of the TB patients were HIV positive. At time of recruitment none of the patients were on ARV treatment.

1.5.2 Households without a patient

The study further identified seven homes without a TB patient. They were drawn from the same wealth group as homes with TB patients. This was important to allow for an objective comparison. During the course of the study, a few people (in Muzoka area) spread rumours about Satanism. These rumours linked ZAMSTAR tuberculin skin tests (TST) to Satanist practices. This contributed to the failure to meet the required number of eight homes without a TB patient.

1.6 Research methods

“Field work is the only (or most important) characteristic of anthropology, separating it from the other social science disciplines, and having done it is the primary badge of membership in the guild.” (Basso Ellen 1995)

I lived in Pemba/Batoka throughout the period of fieldwork (10 months) and worked closely with a local woman research assistant – Florence Moyo a Tonga by tribe. Florence is a trained counsellor. She is an active member of the local clinic in Choma District and is very familiar with home-based care practices in the area. She has lived in the area for

more than twenty years and has worked with anthropologists in similar studies before. She stayed and worked with me for the duration of the study. She accompanied me in the field and assisted in conducting the interviews. She played a role in clarifying transcriptions and recordings, and offered insight into the language and cultural aspects of life that needed elucidation.

In the first month of fieldwork, I facilitated focus group discussions with elders¹³ and community health workers based in the clinics. The focus group discussions were used as a chance to introduce myself and the study to the community. Focus group discussions focused on timelines of food flows, well-being and wealth ranking of Pemba/Batoka, seasonal calendars for hunger, work, income and expenditure, and the impact of TB and HIV/AIDS on households. These were done in order to learn about the community itself, people's perceptions of TB, HIV/AIDS, food security, poverty and wealth issues. These focus group discussions also provided a baseline and a general understanding of Pemba/Batoka and the people in this area, social dynamics, prices of commodities, challenges facing TB and HIV/AIDS patients, and activities of people throughout the year.

I also spent time at the hair salon chatting and listening to women gossip. I had met the owner, Pretoria, the day I moved to Pemba. My first home in Pemba was at a guesthouse, a tiny old building that rarely had guests. Pretoria's salon was right behind the guesthouse and very close to my window. Through the long hours spent in the hair salon, I came to meet and know many women. I also learnt a lot about Pemba in general. With Pretoria's help, I was also slowly learning the language.

Apart from spending time in Pretoria's salon, I also spent a lot of time with the family that owned the guesthouse. They treated me like a family member and were always eager to explain one or two things that I did not understand about the Pemba/Batoka area. After I came to know about the general way of life of the people in Pemba/Batoka, I then focused

¹³ Elderly people that have lived in Pemba for many years and who are very familiar with the way of life in the area.

more on the people who were living with TB and HIV and the comparative families. However not entirely forgetting about other people in the community because they too had a big role to play regarding how people with TB experienced their lives.

In both households with a patient (hereafter - affected household) and households without a patient (hereafter non-affected household), interviews with household heads were conducted. These provided information on household composition, mobility, migration, linkages with urban/rural kin, assets, fields, livestock, harvests, and sources of household income, skills, external assistance (other than that related to TB), social networks and treatment.

Interviews and discussions were also held with TB patients and caregivers. The main reason for conducting interviews with persons suffering from TB and caregivers was to record the direct and indirect costs¹⁴ to patient and household from the onset of illness and during search for diagnosis; food desires and requirements during this period; availability of and access to food aid and welfare support; and access and uptake of ARVs.

Interviews with the key woman in each household were conducted to obtain information on sales and expenditure, morbidity, food stores (at the time), seed stocks (at the time), meals (source) and social networks (which individuals/groups were turned to for assistance with TB illness, HIV/AIDS, food shortfalls)

In addition to these methods, during my 10 months stay in Pemba/Pemba, I participated in most of the daily activities as a member of the community. I spent as much time as I could with people, particularly the nine families and the comparative families and joined in the activities performed without having to carry a pen and paper all the time. This was very important because my topic of study was sensitive¹⁵. For that reason, to carry out effective

¹⁴ Direct costs - transport, food cost, payment for treatment and diagnosis. Indirect costs - number of working days lost due to illness, reduced income due to illness, loss of productivity in medium term.

¹⁵ It is not an easy task to talk to people about their HIV status or about the food they ate the previous day (especially in a poor rural setting)

fieldwork I had to develop a rapport with the community members, though at the beginning of my fieldwork I almost forgot about this - as will be seen from the text below taken directly from my fieldwork notes. But I imagine this was because I was very anxious to get all the information at once. I later came to learn that I had to spend more time with the people and chat, get to know them, and understand their way of life and - through this - I would eventually learn more.

I had a good time at the Hibajenes today. It is interesting how people open up and talk freely once you get to know them and they come to trust you. Today Molly talked freely about her HIV status and her trips to the ARV clinic. I remember the first conversation I had with Molly she was not willing to talk about her status. On the first day I asked her if it was okay for her to share with me her status and she clearly said no. But what really surprised my research assistant and I was that at the end of the interview we asked her if she had questions or anything to say, she went on to say that she wished ZAMBART could provide ARV services at the clinic because it was costly to travel to the next town for ARVs. From her statement, we then concluded that she was positive. But I guess we were in a hurry to get all the information at once. My biggest lesson today is to take it slow and everything comes flowing.

(Field notes, 25 January 2007)

Gilbert Herdt (1991:172), an anthropologist from San Francisco State University, in his work on ethnographic issues in the study of AIDS points out that “respondents, we are learning, are more willing to accurately relay intimate experiences to a trusted person.....such experiences near examination require a special rapport”. My research assistant, Florence Moyo, also helped me in developing a good rapport with the people I worked with.

1. 7 Ethical dilemmas

By definition the research participants were vulnerable and their rights had to be protected. Therefore, I had adequately prepared for my research - Ethical clearance was obtained for the study from the University of Zambia’s Ethics Committee. I also took time to explain

the study to chiefs¹⁶ and key figures¹⁷ in the community and to all participants. All participants were sufficiently informed about the study, including their right to refuse to take part or to withdraw at any time without penalty. Written informed consent was also obtained from all study participants.

Confidentiality was one of my core principles. Every effort was made to ensure the confidentiality of participants in the study as some of the issues discussed were personal and all names and addresses were withheld and were not linked to participants in my notes and work. In addition, as a researcher I was aware that codes of ethics for researchers are very vital because they offer guidelines on how to protect human beings from exploitation and abuse. I therefore, read different codes of ethic from relevant ethical bodies, the Association of Social Anthropology Southern African 2005, American Public Health Association, American Anthropological Association and Association of Social Anthropologists of Aotearoa /NewZeland.

However, although I had made all these preparations, during the course of fieldwork I faced challenges. Asking about food in some detail but not being the position to give food assistance quickly proved awkward. There was also, some pressure sporadically put on me to reveal the HIV status of the participants to others in the community, or to gossip about household visit with others. As a researcher I responded to this pressure by reiterating the importance of confidentiality.

Encountering pain, suffering and death, particularly early on in treatment when patients were still very ill or when patients were close to death, was disturbing for me. The participants too, were disturbed and many cried on several occasions during fieldwork. Although all I wanted to do was burst into tears, I would not for the sake of the participants. This way the participants saw a strong individual who was there to listen. In listening, we developed a friendship of trust. The disturbing emotions experienced by the

¹⁶ Chiefs are the main leaders of the communities I visited, therefore it was very important for me to introduce myself and the study to them.

¹⁷ Counsellor for Pemba, Advisory boards, priests, clinic staff, etc

participants and me show how research can inflict pain on the researched and the researcher. I dealt with this pain through empathy and distancing, and practised my counselling skills. By doing so, I stayed strong not only for me but for the participants too. The openness of households during crisis, experienced by this research, also creates a dilemma; in a sense research almost takes advantage of this vulnerability to expose household dynamics and stresses.

My experiences during fieldwork made me realise that in dealing with ill persons a researcher can not have a complete guide on how to carry out research. Dealing with illness such as HIV/AIDS and TB in poor settings brings new challenges each day for a researcher and thus the best tools for a researcher are respect for participants, confidentiality and empathy.

1.8 Chapter Outline

To ease the reading of this thesis, I shall briefly comment on the structure and content of the chapters to follow:

In Chapter Two, I present the cases studies of the nine people who suffered from TB. The case studies give a brief history of each person - age, economic activity before TB, and how the person was diagnosed with TB. The chapter also shows the kinship networks of each of the nine participants in this study.

Having thus introduced the nine people who form the basis of this work, Chapter Three goes on to examine the larger social context in which the nine people live. The main argument in this chapter is that rural poor of Pemba/Batoka who suffer from TB operate in an environment that has very little assistance from government, non-governmental organisations or the extended family. In the same chapter I further show that, as the person is diagnosed with TB, his or her mobility reduces and space contracts to a point where it negatively impacts on the person, because it reduces the degree to which assistance can be shared across the dispersed network of kin and friends.

When people operate in an environment that has limited support from both government and NGOs, the impact of illness or any form of suffering is great because the huge role of care falls on sick individuals and their households. Chapter 4 therefore, dwells on the impact of ill health and argues that it is difficult for the rural poor of Pemba/Batoka to manage TB and HIV. The chapter has three sections. The first section looks at food security and argues that, due to illness, poor households become even more food insecure because farming patterns are disturbed. Apart from problems of food insecurity, poor households also are faced with the problem of medical costs. The second section explores the problems the rural poor face trying to obtain treatment for TB and AIDS. It demonstrates that if people are co-infected with both TB and HIV, costs are increased as people access ARV services. By using an observation that I carried out in Choma at an ARV clinic, I show that it is very difficult for the rural poor to access ARVs because substantial costs still remain such as travel expenses, especially when repeat visits are needed. The last section of Chapter Four examines how households survive when they are faced not only with TB, but both HIV and TB.

Chapter Five, like Chapter Four, deals with the impact of TB and HIV, but unlike the previous one it delves deeper into people's emotions. The main argument in this chapter is that the impact of illness in the absence of welfare support can result in relationship breakdown, emotional stress and stigma.

Chapter Six is an evaluative chapter. The main question in this chapter is, "Did the outcome of TB/HIV lead to tipping¹⁸?" To answer this question the chapter examines the experiences of the nine people who participated in the study and establishes if tipping took place.

Chapter Seven delivers an overall conclusion to the thesis with a few recommendations.

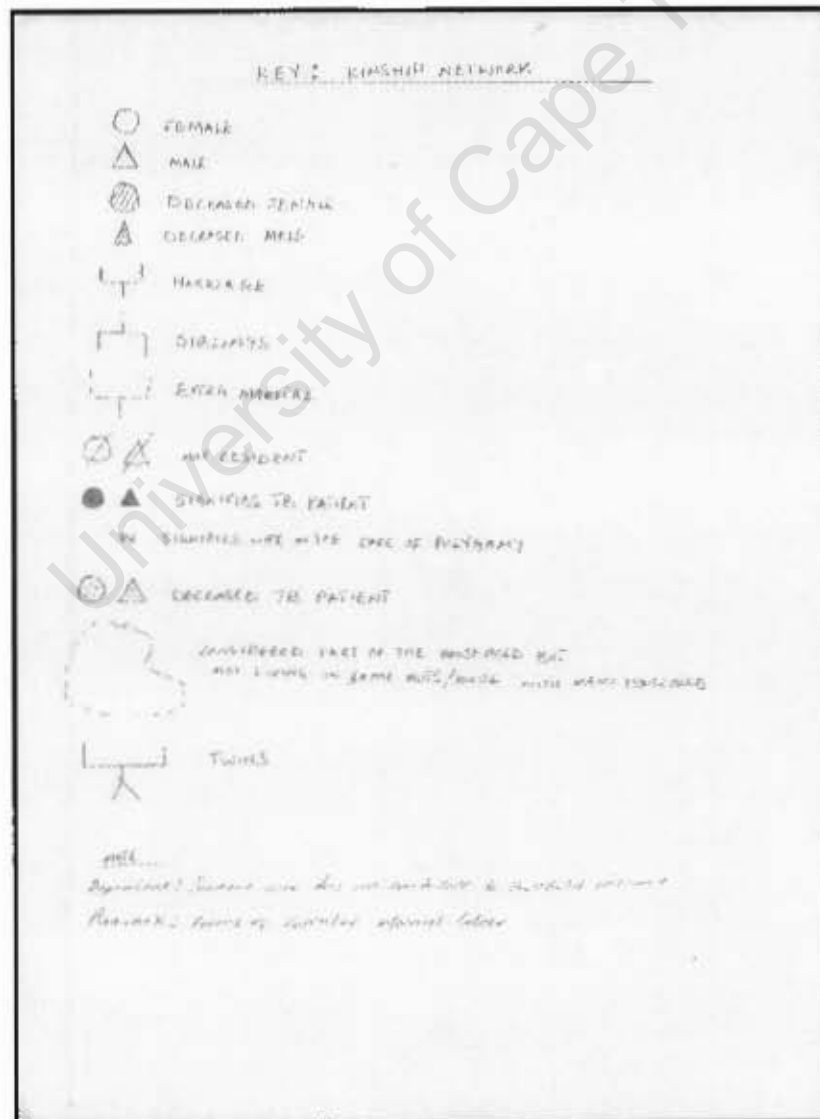
¹⁸ Tipping in this thesis means moving from a higher status to a lower status

CHAPTER TWO

CASE STUDIES

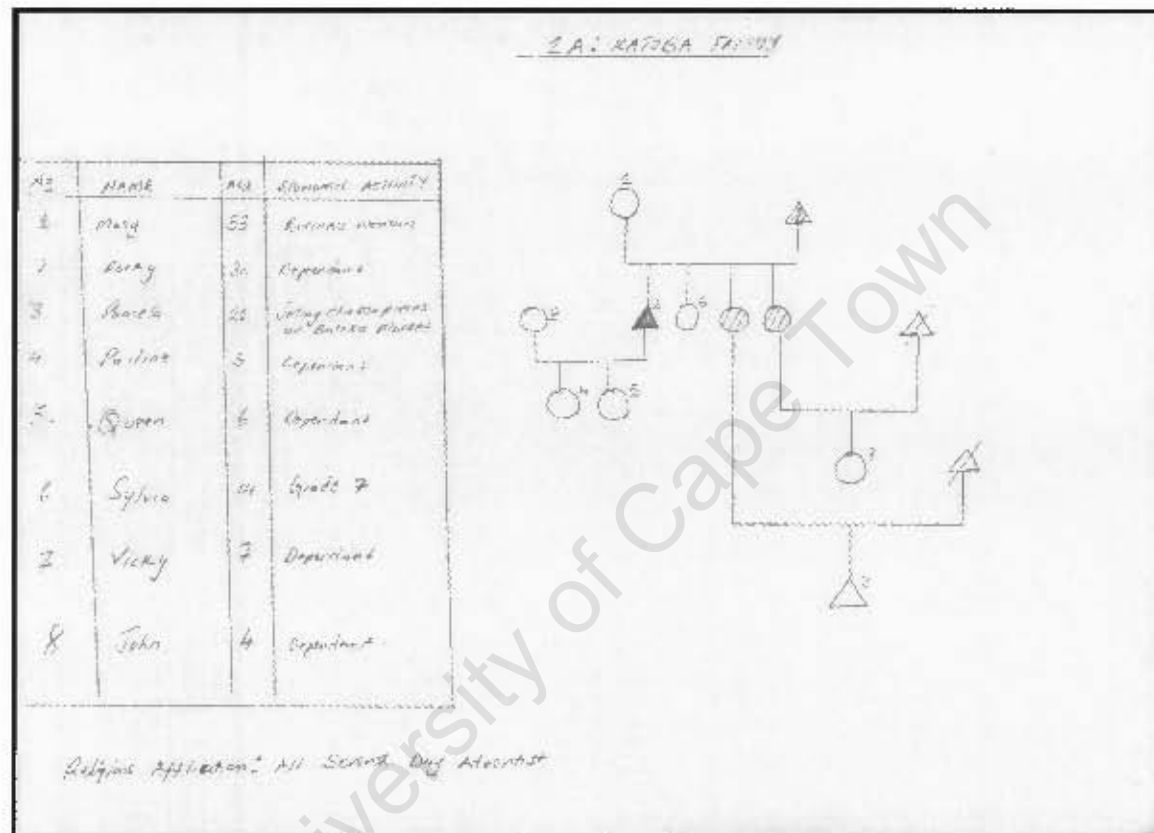
This section presents the case studies of the nine people who suffered from TB. The first chart shows the key to all the kinship network charts of each case study. The network charts themselves show the age of each family member and the economic activities of all household members.

Figure 6: Key for kinship network charts



2.1 Case study 1A: Rocky

Figure 7: Rocky's kinship network chart



Rocky's health problems did not only begin when he became sick with TB. In 2005, before he showed any symptoms of TB, Rocky lost his job. At the age of 29, Rocky was lucky to work as a farm labourer at a commercial farm owned by a white man. This ended when he broke his arm while at work and was sent on sick leave. Once an active contributor, Rocky became dependent upon his mother's income to sustain their household. Moreover, there are many people to feed in Rocky's household.

Before Rocky's arm healed, he fell sick with what would eventually be diagnosed as TB. In May 2006, Rocky began coughing. He experienced body pains and lost weight. To treat his illness, he used herbs and other traditional medicines but these did not cure his

symptoms. He then went to a chemist in Batoka Market and bought paracetamol (panadol) and other drugs. This cost him the equivalent of one US dollar. For two weeks, he took the medicine from the chemist but that did not cure him. He decided to visit the clinic, which is 5km from his home. At the clinic, he only received paracetamol.

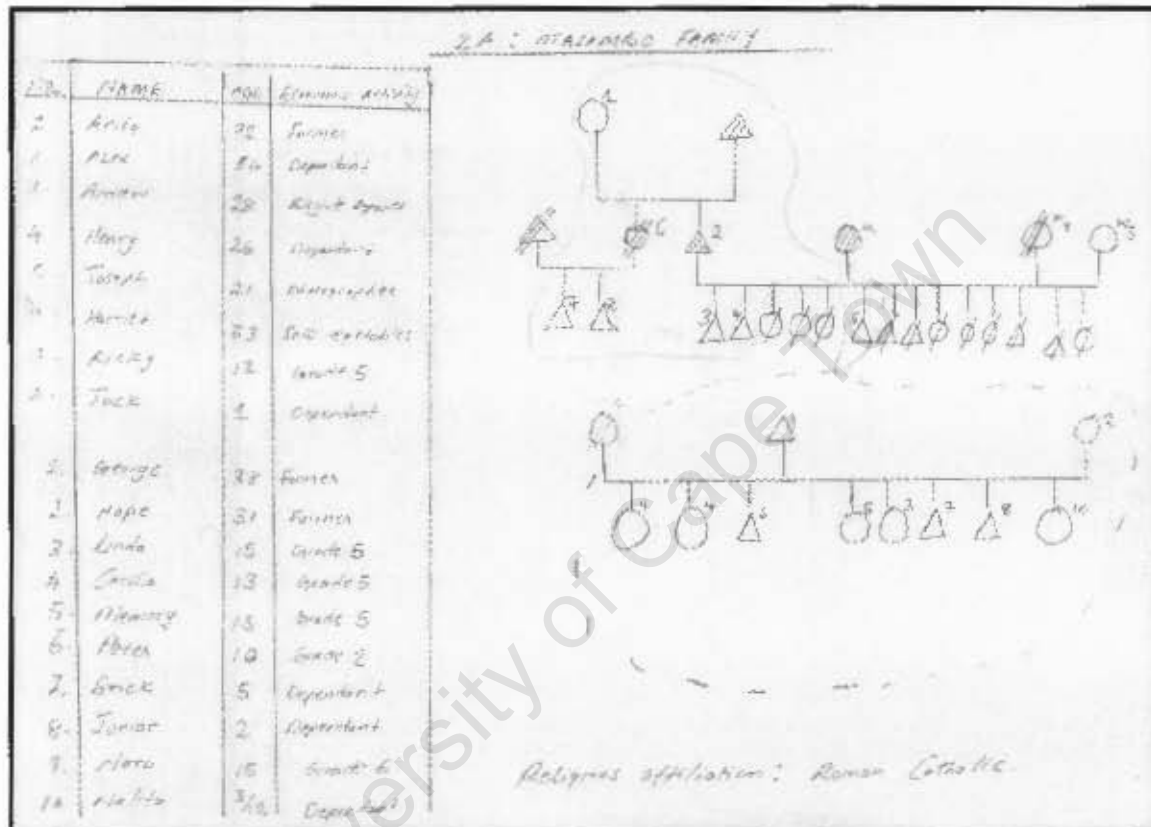
For months he visited the clinic and each time he was given paracetamol with no diagnosis. When he became seriously ill in August 2006, the clinic would no longer handle his case. He was referred to Choma Hospital. He and his mother Mary spent almost K12 000 (R23.00) to get to Choma. It was at Choma Hospital that he was finally diagnosed with TB. Rocky, his mother Mary and his wife Pamela also tested for HIV - an option offered to them by household counsellors with the ZAMSTAR Project. After counselling, Rocky and Mary tested HIV positive. Pamela was HIV negative

By the time I met Rocky's family, Mary had used much of her money and time in search of a cure for Rocky's illness. Two of her daughters died in 2005 and Rocky became sick around the same time. She suspected witchcraft and visited traditional healers to find answers. Ashforth explains that witchcraft provides a framework of moral agency that makes sense of seemingly random coincidences in space and time. "The invocation of 'witchcraft' provides ways of answering the questions: why me or he or she?" (2001: 6). Mary wanted answers to why she had lost two daughters in a short space of time and why her son was ill.

When Rocky started to feel better, Mary began a business of selling wild fruits and mushrooms. During the rainy season, mushrooms and wild fruits are plenty in Pemba/Batoka area. She raised enough money to start a business selling second-hand clothes but, in March 2007, she fell ill and could not continue with the business. Apart from money problems, food was also hard to come by for the family.

2.2 Case study 2A: Alex

Figure 8: Alex's kinship network chart



In October 2006, I met Alex Malambo, then 54 years old. Alex had lived in Pemba most of his life. He was married to Mutapana, his third wife. They had 2 children, Hilda (7) and Brian (4). Alex had five children with his first wife who had died, and seven children with the second wife who he divorced. At the time I met him, Alex was only living with three children, Hilda, Brian and Henry.

Alex's Pemba home is right behind Pemba clinic. It is a three-roomed house made from burnt bricks with a thatched roof. Outside the house are old rusty vehicle and motorcycle parts - a sure sign that a mechanic lives there. Alex used to work as a mechanic; he repaired vehicles and motorcycles at a garage in Pemba. He had never considered himself at risk of getting infected with TB such that when he started experiencing headaches, body

pains and night sweats early in 2006, he thought he was suffering from malaria. On his way home from work he passed through the clinic and collected the Malaria drug Fansidar (Sulfadoxine-pyrimethamine).

After a week, he did not feel better so he went back to the clinic and this time he was given quinine. The quinine affected his ears and he developed a hearing problem, but it did not cure the symptoms of TB. The symptoms persisted, he was getting worse, he tried different medicines at the clinic but they did not help. The nurses urged him to go for VCT, which he did, and was found HIV positive. The nurse gave him a referral letter to Monze Hospital for ART investigations but he did not manage to go due to lack of money. When he finally found the K20 000 (R38.68) that would take him to and from Monze Hospital, 40km from Pemba, he travelled there, but unfortunately he found the CD4 count machine not working and the clinic had run out of ARVs, so he was given an appointment for a different day.

Alex went back home, but he was getting worse by the day; his legs were swollen and he could no longer walk. He became seriously ill and his family had to book a taxi to take him to Choma Hospital, 60km away from his home. At Choma Hospital he was diagnosed with TB and admitted for two weeks. The taxi to the hospital cost K100 000 (R193.40) and during Alex's admission another K100 000 was spent on food and transport money for Mutapana who had to go and check on the children every now and then.

After Alex was discharged, the family faced financial problems. With no employment and due to his illness, Alex could not provide for his family. This situation was made worse by the subsequent sickness of Mutapana. She was diagnosed with HIV and was put on antiretroviral treatment. She took the children for HIV testing and they too were found to be positive. This left the family physically and emotionally drained. With this critical situation in the household, "town life" became impossible for Alex and his household. He and his son Henry were forced to move from Pemba town to the village in Kasiya, where his mother was. With the support of his mother and kin in Kasiya, life, according to Alex, would become manageable. Not everybody followed him to Kasiya. His wife, Mutapana

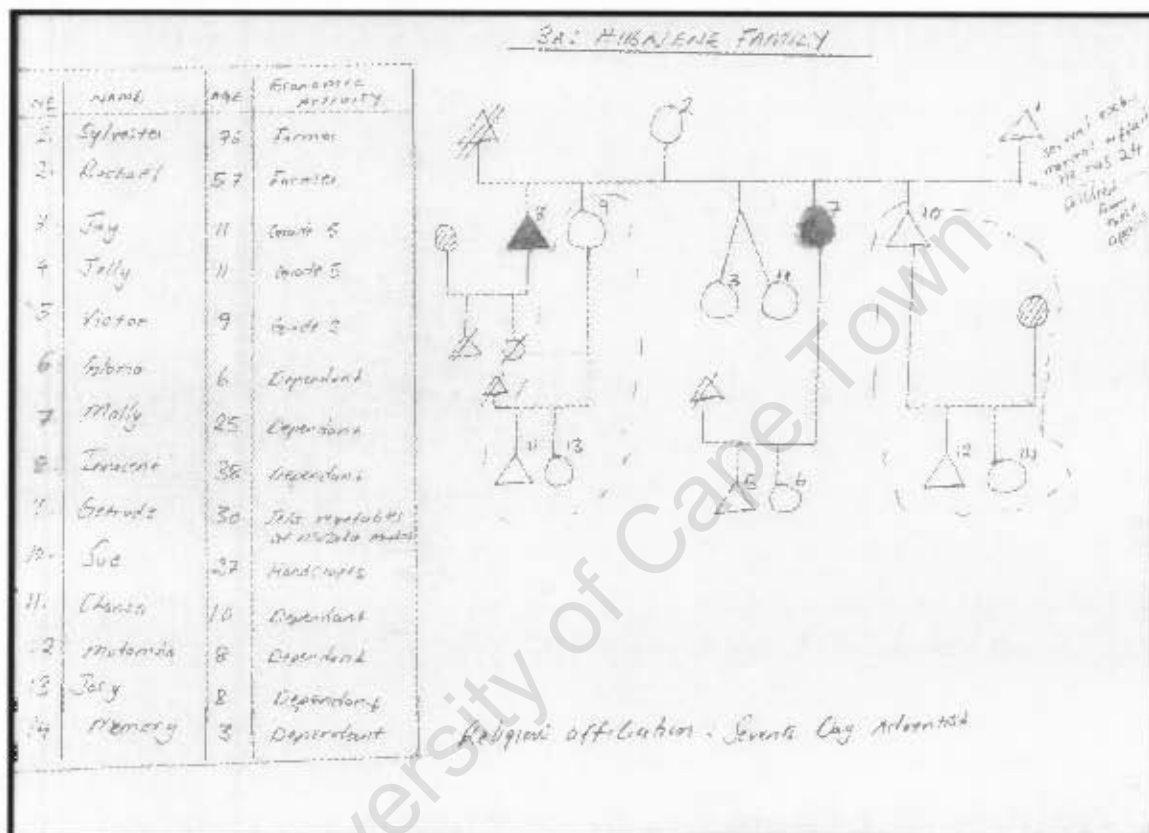
resorted to going to Kapiri-Mposhi¹⁹ to her mother's place. The children (Hilda and Brian) were taken to Mutapana's aunt in one of the villages in Pemba.

At his mother's place, Alex was isolated from everyone. He never left his bed unless it was time for his bath. Unfortunately, he died before he could be cured of TB.

¹⁹ Kapiri-Mposhi is found in the central Province of Zambia and is 430km from Pemba.

2.3 Case study 3A: Molly and Innocent

Figure 9: Molly and Innocent's kinship network charts



Sylvester Hibajene, a 70-year-old man lives with his wife Rachael in Muzoka. Sylvester has lived in Muzoka for 27 years. Before moving to Muzoka he worked as a teacher for the Ministry of Education in Kalomo, 107km away. When he retired in 1989, he opted to migrate and settle back in his village Muzoka.

Sylvester's wife, Rachael, had five children with her first husband who she divorced before marrying Sylvester. Her first-born child from the first marriage is a 38-year-old man called Innocent. While married to Sylvester, Rachael gave birth to six more children. One of the six is a woman named Molly.

Molly is 25 years old and used to work as a teacher at a community school in Luapula

Province of Zambia, where she lived with her husband and her three children. In 2005, her last-born child died, and she was left with two. After her child's death, she started feeling sick. She fell very ill, such that she was forced to leave and go to her parents' home in Muzoka for fear of dying. Her husband would not take care of her because they had marital problems. She packed her bags, took her children and travelled to Muzoka.

In Muzoka, Molly was diagnosed with TB. She was put on TB drugs but did not manage to complete the course because, as soon as she was feeling better, she decided to join her half brother Innocent in Kitwe, a town in on the Copperbelt Province of Zambia. She left her children behind and decided to go to Kitwe with a hope of finding a better life, because life in the village was difficult. According to Molly, it was difficult in the sense that food and money was hard to come by.

In Kitwe, Molly worked at a guesthouse while Innocent was a horse-minder at a commercial farm owned by a white man. In early 2006, Molly fell ill once more. It did not occur to Molly that this would be a TB relapse. She started feeling very cold and had pains - she thought it was malaria. She went to Luangwa Clinic in one of the shanty compounds in Kitwe where she was given Fansidar. *"After taking Fansidar I felt better for two weeks and then I started feeling sick again. I went back to the clinic and I was given painkillers. The painkillers did not help much and I went back to the clinic but this time I told them to refer me to the hospital,"* Molly narrated.

At the hospital, she was given two injections, penicillin, aspirin and a prescription to buy more drugs. She took the medicine for two days and when she noticed that she was getting worse instead of better, she decided to go back to Muzoka. In Muzoka, she visited Muzoka Clinic and she was given more Fansidar. She got very ill and was rushed to Choma Hospital.

Sylvester spent over K200, 000 (R387.00) on transport to the hospital for his wife, Molly and himself, and on food during Molly's admission and other things that Molly required like soap and tissues. During this time, back in Kitwe, Innocent became critically ill.

While Sylvester, Rachael and Molly were in Choma, Innocent was on his way to Muzoka.

When I met Innocent on 22 November 2006, he was very sick; he was tall, thin and had no single healthy hair on his head. He was breathing heavily and his voice was shaky. Not wanting to miss a word of what he was saying, I sat close to him and listened carefully as he shared the following.

“My illness started in my sleep. On Sunday morning I was supposed to take my sister to the bus station because she had not been well, but at night around 04:30 hours I dreamt that I had a stitch on my left side. I woke up, sat on the bed, and found that I had real pain on my left side. I forced myself to walk outside so that I would wake up my sister. She woke up and started preparing herself for the journey. I went back to sleep. Around 06:00 hours I escorted her to the bus station. At that time, I was really forcing myself to walk; I had to be strong like a man. When the bus left, I went back home and slept and that was the beginning of my illness.

I bought brufen and panadol from a small shop (ntemba) but later went to the clinic. At the clinic, I was given drugs. The drugs I was taking made me weak so I lost a lot of strength.

After taking the medicine, I felt much better but after some time, I started feeling sick. By end of the weekend, I was too sick. My boss booked a vehicle to take me from Kitwe to Muzoka. It cost K400000.

In Muzoka, I did not find my parents because it was the day that my sister was discharged from Choma Hospital. I found my other sister who prepared a place for me to sleep. I slept under a tree and that is where my parents found me. The following day my parents took me to Muzoka Clinic. At Muzoka Clinic, I was referred to Choma Hospital where I was later admitted. I am not sure where this TB came from. I cannot say that I got it from my late wife because maybe I am the one who brought TB into our home.”

Two patients at the same time were too much for Rachael. Earlier in the year, Rachael was

nursing her daughter in law who later died²⁰. Rachael and Sylvester had the responsibility of arranging for the funeral because the girl's relatives were not "cooperative", according to Rachael. During the same year Rachael's father died. Rachael was emotionally and financially strained when Molly and Innocent came to live with her. When both Molly and Innocent were much better I asked Rachael to tell me about the first days when Molly and Innocent had come back from Kitwe. *"I went mad. It was too much for me. I would not believe what was happening; I asked God why such a thing was happening to me,"* Rachael recalled.

It was indeed not an easy task for Rachael and Sylvester. Most of their time was spent caring for the patient. This left them with very little time to work in the field. Things were getting worse by the day: both Molly and Innocent continued to lose weight; Molly complained of ear and stomach pains and, at one time, she was suspected of being pregnant. Innocent complained of swollen legs and a rash on his body.

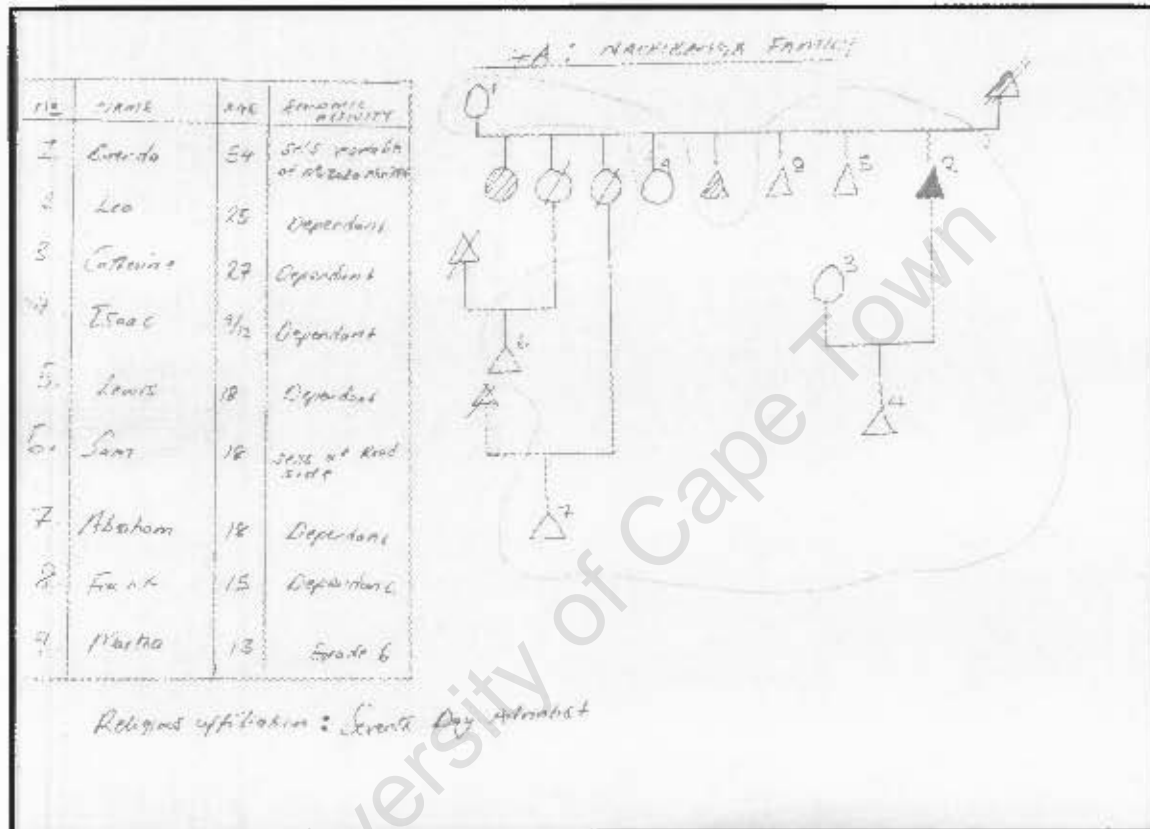
The only way to help them was to try to access ART services fast. This too proved difficult. Sylvester's only source of cash was a K50 000 (R96.76) which he received each month from his pension money through Finance Bank. The K50 000 was not enough to survive; Rachel sold some of her clothes, sold some livestock and borrowed money from friends.

Sylvester borrowed more money so that the two patients could visit the ARV clinic and start accessing the drugs as soon as possible because they were losing weight fast. By the time Innocent and Molly started taking ARVs, the family had accumulated debts. Both Molly and Innocent were cured of TB but Rachael and Sylvester were left poorer than before.

²⁰ She was married to Sue. Sue and his wife were both HIV positive. Sue is still alive, he lives with his daughter.

2.4 Case study 4A: Leo

Figure 10: Leo's kinship network chart



Leo was born in 1981 in Muzoka. At 19, he migrated to Mazabuka - over 100km from Muzoka - where he started a business of selling audio and videotapes. At 21, he married Catherine, and they have a son called Isaac. When he married Catherine, he moved from his one room house into Catherine's home, where she lived with her mother. Through the video business, Leo used to earn close to K3000000 per month. He supported his new family, his mother and siblings from the money he earned.

Leo's mother, Brenda lives in Kalyengu Village in Muzoka. It was at Brenda's home that I met Leo. Brenda, a divorcee, lives in a small burnt-brick house, which has three rooms. In the middle room is a set of old green sofas, a broken green fan, and five photos of herself with her children hanging on the wall. The house and a *chikuta* (kitchen) are the

only structures at Brenda's compound. She does not have a pit latrine or *butala* (grain bin) like other households in the area but shares a pit latrine with a neighbouring household.

In December 2005, Leo fell ill. He was in and out of hospital and each time he was diagnosed with malaria. In September 2006, he had swollen glands, pain on both sides of his chest and was too weak to walk. He was admitted to Monze Hospital for three weeks. During the three weeks, he finished a malaria course and other medicines that he was given but there was no improvement. At the end of September he went back home but, during the week that followed, he was taken back to the hospital because he became seriously ill. Two admissions in a short space of time was a financial strain on Leo and his mother. On 25 October 2006, an X-ray was done and he was finally diagnosed with TB. He was also tested for HIV and was found positive. When Leo was diagnosed with TB, he became too ill to maintain his business. He moved to stay with his mother in Muzoka.

Life was not easy for Leo and his mother. During the ten months I lived in Pemba/Batoka, Brenda struggled as a petty trader selling tomatoes at Muzoka Market. Every time she made a profit, it was used for transport to Monze Hospital. The main source of income for the household was usually borrowed money and piecework done by Brenda. Leo in turn was selling off his clothes to raise more money for transport to the hospital. Leo made countless trips to the hospital since at one stage the doctor at Monze Hospital thought Leo was wrongly diagnosed, and was not actually suffering from TB but from a different disease that had not yet been established. This meant Leo had to make many trips to the hospital for more tests. By the end of my ten months in the field, Leo had used over K1 000000 on these trips.

Due to financial constraints, Leo began to quarrel with his mother. Whenever Leo sold any of his clothes, his mother requested the money. After four months of living with his mother, in the last week of January 2007, Leo ran away from home and went back to Mazabuka. When I went to visit Leo in Mazabuka he was in a terrible state, he had lost weight and his face was swollen. During my visit, Leo recalled why he had left his mother's house.

“While in Muzoka I sold my pair of shoes. My mother asked me to give her the money so that she could buy fertiliser. I refused to give her because I was depending on the same money as transport money to the hospital, and we quarrelled. After that, she was angry with me and sometimes, she used to leave me alone for a long time without a bath or water for drinking. I knew she was punishing me for not giving her the money. I could not take TB drugs because there was no one to give me water. I was too weak to move. Therefore, when I felt better I decided to come to Mazabuka.

When I reached Mazabuka, I went to my mother-in-law’s home because that is where I used to live before I fell ill. My wife’s relatives chased me during the night before I could dress. I ran to my half brother’s house.

I think my wife is annoyed with me and she does not want anything to do with me because I do not have money and she cannot have the kind of life she wants. There is no marriage between us. From the time I came to learn about my HIV status there has been no marriage.”

By running away to Mazabuka, Leo thought life would be much better, and he did not expect the treatment he received from his in-laws. At his half brother’s house, life only got worse. He was made to sleep under a table far away from his brother’s children because the brother feared he might scare his children with his swollen body. His brother also feared that Leo might infect his children with HIV.

“Imagine: I have not had a bath for the past one week. No one has collected water for me. I am too weak to do it myself. I sleep under that table. I sleep far from the children because I can scare them with the way I look. I have suffered; life is hard for me,” Leo narrated in between sobs.

After facing so much stigma, Leo realised it was better for him to go back to his mother in Muzoka. *“I think I am better off at my mother’s. Though she talks too much I am free and I sleep comfortably. I am better off at my mother’s than this kind of life where I sleep*

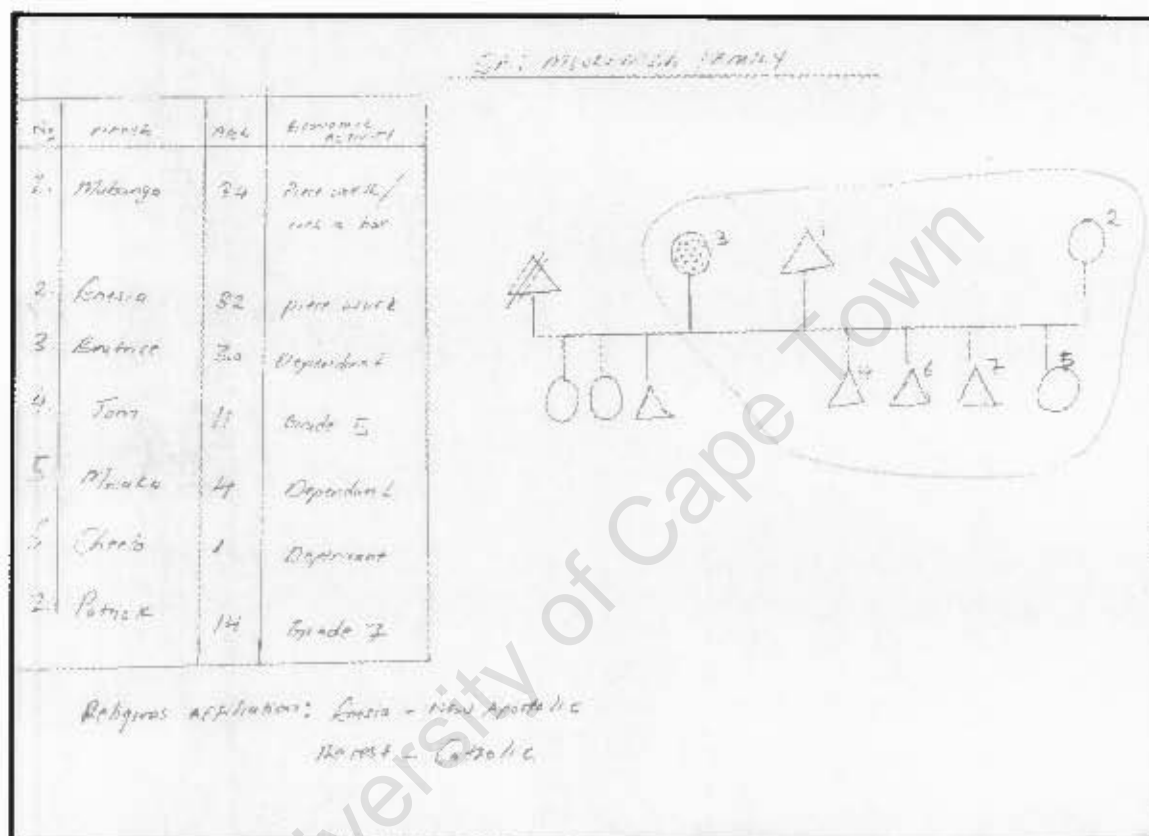
under a table." On 7 February 2007, Leo went back to Muzoka.

By April 2007, Leo had sold most of his special clothes and had nothing else to sell. His mother had used up all her capital and was relying on borrowed money. They completely ran out of food. To survive, Brenda begged for food from friends at the market but this was not sustainable. Due to lack of a proper diet, Leo was not improving. At six months into treatment he still looked very weak, and his face and neck were swollen. He had started taking his ARVs too, but still, there was no change. In addition to this, Leo used to have nightmares; *"In my dreams I met people who used to take me to places I have never been. At those places we used to kill animals and eat them raw. In the morning I would vomit and experience general body pains."*

His mother believed someone was trying to bewitch him. Leo too, believed someone was trying to bewitch him. The trip to the traditional healer marked the end of Brenda's capital. She had no money left and survived by begging. By the end of my ten months fieldwork in Pemba/Batoka, Leo had finished taking his TB drugs, his neck was no longer swollen and he looked fine.

2.5 Case study 5A: Beatrice

Figure 11: Beatrice's kinship network chart



The Mweemba family lives in Hamazongo Village in Pemba. Mubanga Mweemba who was born in 1972 used to live with his wife, Enesia and their three children Patrick, Tom and Mwaka. When Enesia was pregnant with their fourth child, Cheelo²¹, Mubanga ran away from home and moved in with his girlfriend Beatrice.

Beatrice was born in 1976 in Batoka. In 2003, Beatrice migrated from Batoka to Pemba in search of work opportunities. When she found a job as a waitress at the roadside bar in Pemba, she basically made the bar her home. She cooked and kept her belongings in one of

²¹ In 2006, Patrick, Tom, Mwaka and Cheelo were aged 14, 11, 4, and 1 and 7 months respectively.

the rooms. The bar is a two-roomed construction made from burnt bricks. Because the place is too small to accommodate all the people that patronise it, the majority of the patrons sit outside under a tree. It was at this bar that she met Mubanga - a shareholder of the business²². They fell in love and in 2004, Mubanga moved in with Beatrice.

By the end of 2004, Beatrice started feeling sick. She treated herself with traditional herbs but the pain did not go away. During early 2005, Beatrice was in and out of hospital but her condition never improved. She tried different treatment options: clinic, hospital, traditional and self treatment, but there was no change in her condition. Mubanga realised that he could not manage to care for Beatrice and so he decided to go back to his wife and brought Beatrice along. In February 2005, Enesia became Beatrice's caregiver.

When I asked why she had offered to look after Beatrice, Enesia answered, *"Little did I know that my husband decided to come back home because his girlfriend was sick. He could not manage to care for her so he came back home and after a few weeks he brought her home. When she came home she was very sick. Though I was hurting I took care of her because her relatives do not care; none of them came to visit her. I felt pity because she is my co-wife and her relatives do not mind or care. If I don't care for her she will die and the problem of buying the coffin and food at the funeral would be my husband's."*

It took almost two years for Beatrice to be diagnosed with TB. Finally, in 2006, Beatrice was diagnosed with TB in Monze Hospital. Enesia was very supportive - she worked hard to find money for food. *"I treat her like my sister; I have to work hard to find money by doing piecework so that we can buy her whatever she wants. I work double shifts, no one helps me out. I get very tired and when I sleep I sleep like a baby. When we run out of food I go to my relatives in Mwala to ask for food,"* narrated Enesia. The fear of funeral expenses motivated Enesia to care for Beatrice for over five months into TB treatment; however, once Beatrice was much better, the two co-wives began to experience problems.

²² The bar belongs to Mubanga's friend. The beer sold at the bar was bought by both Mubanga and his friend and the profits are shared.

Enesia complained about Beatrice and vice versa each time I visited. To make matters worse, Beatrice tested HIV positive and Enesia stopped caring for her. Beatrice further explained that Mubanga had stopped spending time with her because of her illness. Her husband told her not to start taking ARVs and, if she wanted to take the ARVs, she should drink them anywhere but in his house.

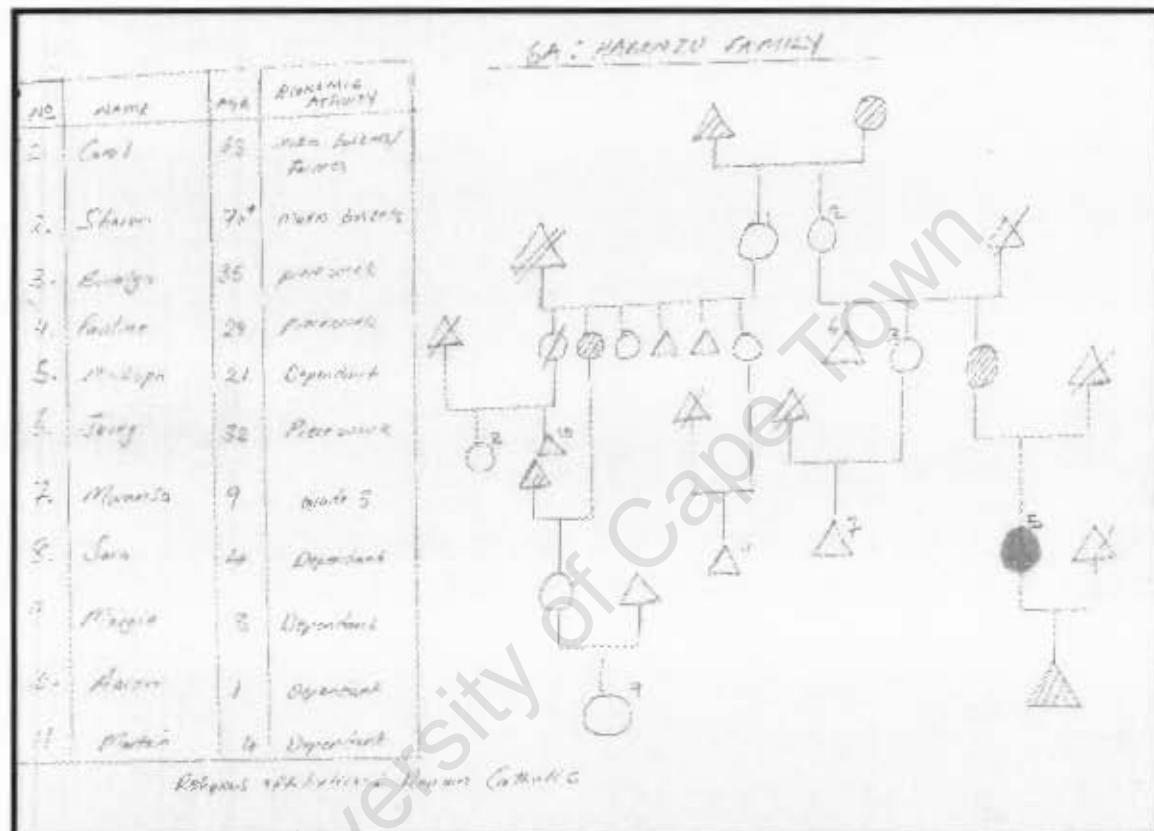
"I am unhappy", narrated Beatrice, "I do not like the way I am treated by my co-wife and my husband. I am not receiving enough care. These days my husband does not pay attention to what I say. He does not want to spend time with me. He does not want anything to do with me. He refuses to spend the night in my house."

Beatrice took a long time to start taking ARVs - though she was willing, she could not find money to go to Monze. On 18 April 2007 she finally started taking ARVs and, by the first week of May 2007, she moved away from Mubanga and Enesia's home to a friend's place. I was in the salon chatting with the women when I heard that Mubanga and Enesia had chased Beatrice from their home.

During my last discussion with Beatrice she was depressed. Although she had moved back to Enesia and Mubanga's home, she complained bitterly about Enesia and how she had treated her. On 15 May 2007, Beatrice died at Pemba Clinic around 16:00.

2.6 Case study 6A: Mukupa

Figure 12: Mukupa's kinship network chart



Mukupa was born in 1981 in Lusaka. Her parents died when she was very young and so she grew up with her sister who lived in Chipata in the Eastern Province of Zambia. While living with her sister, Mukupa married a man who lived with his parents. They had a child but, due to that fact that her and her in-laws lived under the same roof, Mukupa began to experience problems in her marriage. She moved out and went back to her sister's home. When her sister died, Mukupa went back to her husband. It was while living with her husband that Mukupa started feeling sick. She recalled how it all started:

"I started coughing and at the same time I had chest pains and swellings around my neck For a week. I drunk some herbs that my mother-in-law had given me but there was no change. It was difficult for me to collect water from the river. When the problem got worse

my mother-in-law took me to the traditional healer but still there was no change. She later advised me to go to the clinic. I went to Chipata General Hospital. I explained that I had malaria, chest pains and general body pains. They got blood and urine. In the blood they found that I had no malaria but in the urine they found that I had STDs. My sister in marriage took me to the clinic. We paid K20 000 to get to the clinic, and for urine and blood tests I paid K10 000.

I went back home but there was no change even after finishing the course. I thought of going back to the hospital but I did not have the money. My son became ill too. I did not know what was wrong with him. My in-laws gave me money to travel to Lusaka. I went to my brother's house in Lusaka but he said that he could not care for me. He gave me directions to the village. I had never been to the village. I did not know anyone but I needed care so I travelled."

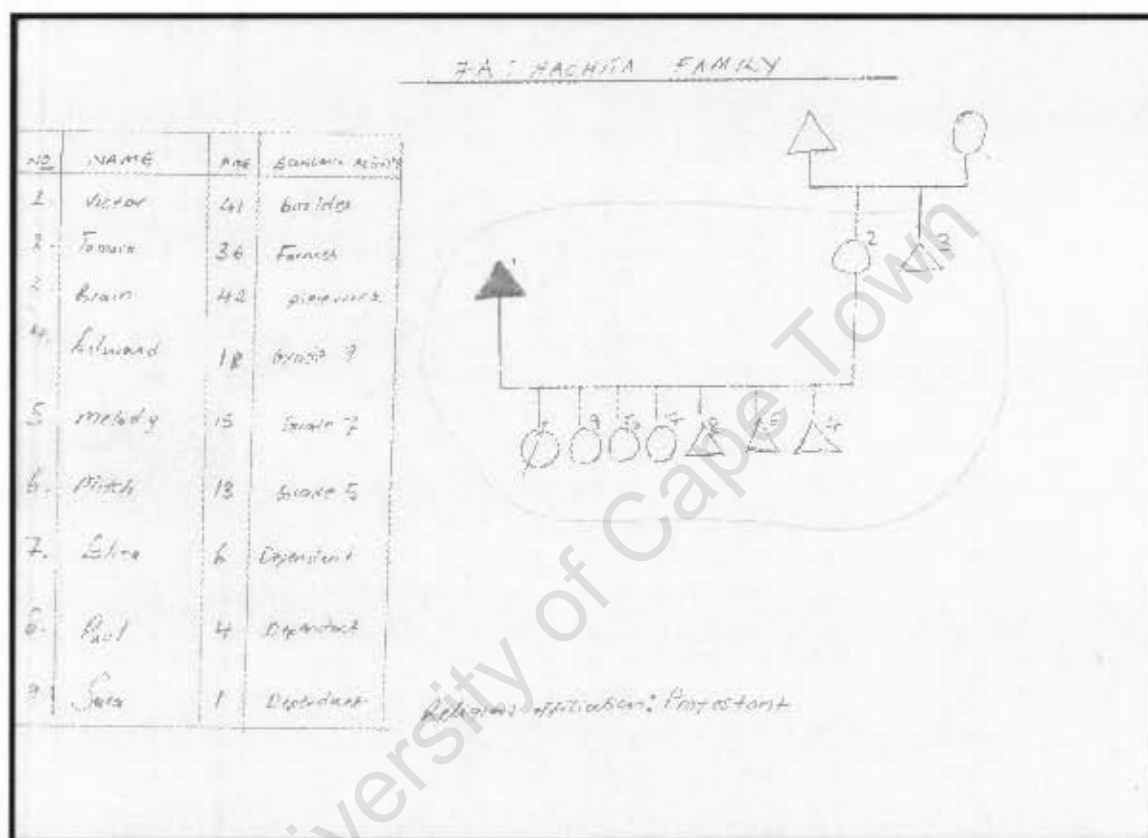
In October 2006 Mukupa travelled to Pemba. She had no idea where she was going. With the help of the local people she finally managed to locate her grandmother who lived in Mwala Village.

I used to see Mukupa at the clinic whenever she brought her child for review. Her child was four months old and very unhealthy. The child was a TB suspect but unfortunately it died shortly after the TB diagnosis. A few weeks after the child's death Mukupa was diagnosed with TB, she had only been in Pemba for two months. Mukupa suspects that she got her TB from her mother-in-law, *"I used to take care for my mother who suffered from TB and one of the nurses had mentioned that I too might suffer from TB in future."*

Throughout the eight months of TB treatment Mukupa was not free to discuss TB or HIV. She always hid her TB illness from people. When asked about it she always said, *"Why should I tell people about TB? They only gossip. I hide that I am a TB patient, I do not share with anyone."* Mukupa's insecurity about her illness became worse when she tested HIV positive. In June 2007, after completing her TB treatment, she moved from Pemba to Lusaka.

2.7 Case study 7A: Victor

Figure 13: Victor's kinship network chart



Victor was born in 1965 in rural Kalomo. He has lived in Batoka for over ten years. He is a bricklayer by profession. Because of his building skills, his compound neatly stands out from the rest, with three houses around the compound beautifully made from burnt bricks.

Victor started feeling sick in July 2006. *"I first started feeling sick in July this year. I had a cough, body pains and lost appetite. I tried African herbs, which my neighbour gave me but I did not follow the course because I was a drunkard I would take the herbs on one day and forget to drink the next. I went to the clinic for treatment and I was given medicine.*

They gave amoxicillin about three courses. I started the first course in July. The second

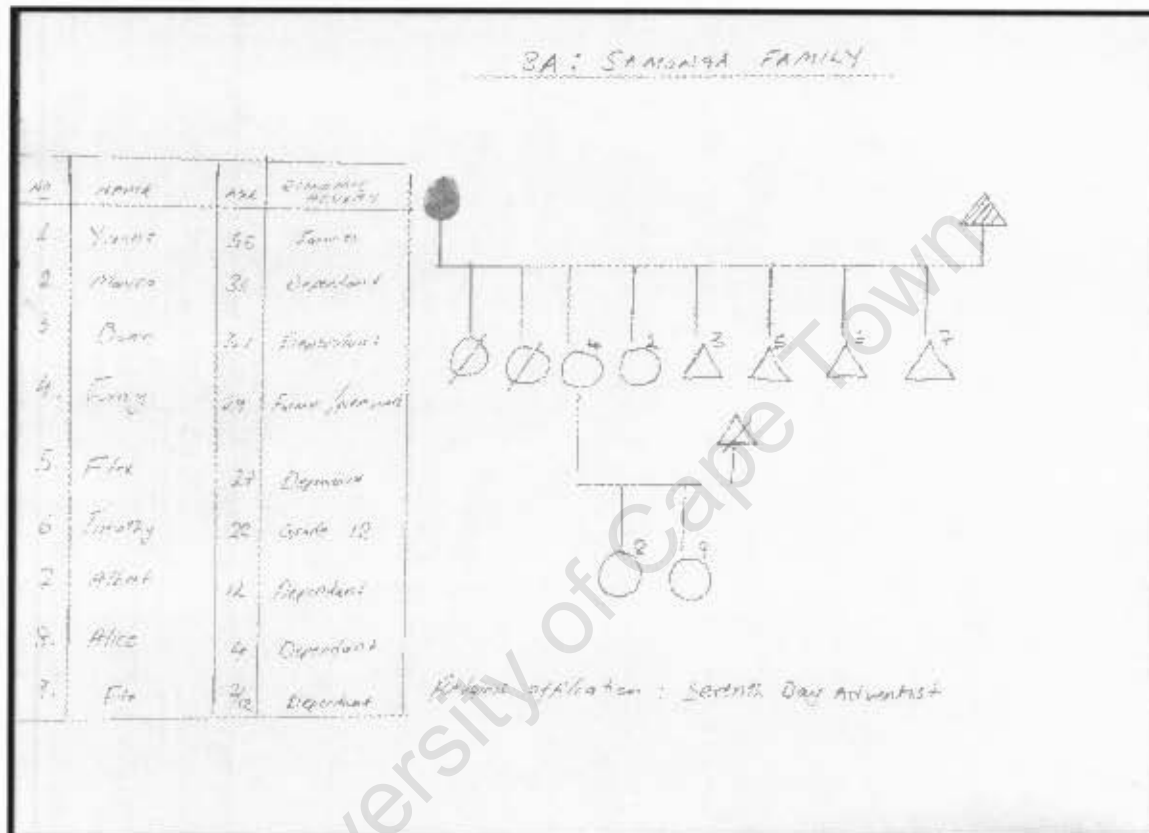
course I was feeling better so I used to take the course on some day and some days I used to go out for beer. When I finished the three courses there was no change.

In October I started feeling very ill. I had chest pains and I could not walk long distances. I went to the clinic and explained to the nurse how bad I was feeling. The nurse told me to take sputum but the results took too long. I continued working because I had to feed the family but it was not easy because my chest was really paining. After work I used to cough the whole night and my chest was in pain it was difficult for me to sleep. When I got worse I decided to go back to the clinic and speak to the clinical officer. The clinical officer examined me and found that I had a problem on my left side, I was not breathing well. He gave me a referral letter to Choma Hospital; I did not have the money so I went to look for money. When I finally found the money I went to Choma Hospital and it was there where I was diagnosed with TB. I started the TB medicine while in Choma and when I came back home I was admitted at Batoka Clinic for two weeks."

Victor was not happy with the results - he never imagined himself suffering from TB. Victor thought he might have inherited TB from his parents. *"Maybe my parents had TB at one time in life."* He feared he would die like them and he also feared that, like his parents, he could pass on TB to his children. *"When they told me I had TB I thought I would be sick like my parents and look as bad as they looked before they died. I do fear that I may pass TB to my family the way my parents passed the disease to me."* Luckily, his fears were not realised - he was cured of TB in June 2007.

2.8 Case study 8A: Yvonne

Figure 14: Yvonne's kinship network chart



I met Yvonne Samonga in January 2007 in Malwiido Village in Muzoka. She is a widow aged 55. She was born in Muzoka and has lived in Muzoka all her life. I asked her to join the study, she accepted, and the following week I went to her home. As Florence and I approached the compound I admired the view because it is situated on a higher level, more like a plateau. Yvonne also has a lot of fruit trees surrounding her compound, mostly bananas, wild fruits and lemon trees. Her compound is very clean with flowers at each hut entrance.

When we arrived at the compound it was raining heavily and we ran straight to the hut that was nearest. In the hut were two elderly men, a young boy and one elderly looking woman. The four were situated around a fire, trying to keep warm. We greeted them but there was

no reply. We greeted them for the second time but no one spoke. We asked them if we could sit down but no one replied. We took some seats and sat with them for almost 30 minutes. During the 30 minutes no one spoke or said a word. I started to worry, and so many thoughts were running through my head. I asked myself if we were not welcome or if the men were dangerous. Finally, when the rain had subsided, a woman of about 25- 26 (I later learnt she was 29) entered the hut and greeted us. She later explained that the four people were her siblings and they were disabled. *"They are dumb but not deaf; they suffer from night blindness and practically cannot do much,"* she explained.

I was saddened by the fact that the two stronger-looking men were unable to work. I had already visited seven households affected by TB before I met Yvonne's household. Of all the households I had visited, I found Yvonne's household to be the poorest. Poorest in the sense that not only was it economically poor but it was also physically poor. Apart from suffering from TB, Yvonne was also suffering from epilepsy and high blood pressure. In addition to this, four of her six children²³ were disabled. Of the two that were able-bodied, one was at secondary school in Pemba and the other, Funny, stayed at home to help her mother with household chores and to look for money to feed the family.

Life became very tough for Funny because she had to do most of the work by herself. *"There is no one to look after the family. Everyone here is like a child they need a mother but now that mum is sick there is no one to care for them. I cannot manage to care for everyone by myself."* Funny has two children with a man who used to live in Kalomo. She wished to go and live with him but since there was no one to take care of the family, she could not go. *"I have a man in Kalomo and maybe he has now moved somewhere else because I told him that I would not go and live with him since there is no one to take care of my mother and the others. He thought I was not interested. No one understands the problems I have,"* she narrated.

²³ Yvonne has six children: Monica (36), Owen (31), Funny (29), Flex (27), Timothy (22) and Albert (12). Monica, Owen, Flex and Albert are disabled.

Before the TB illness Yvonne was able to send her disabled children to a special school called St. Mulumba in Choma, 42km from Muzoka. She raised money through piecework and selling at the market. But when she fell ill, became bedridden, and was later diagnosed with TB, her children dropped out of school. *“My children were at St. Mulumba School in Choma but they have stopped school due to lack of school fees,”* Yvonne explained. Life was already tough for Yvonne; and TB had added more misery to her life.

2.9 Conclusion

The case studies of the nine people show how the synergy of co-infection with TB and HIV plays out for affected individuals and their households in the context of poverty and overstretched public services. From the case studies it is clear that patients experienced a protracted diagnostic search, an indication of how slow the clinic is to suspect and test for TB; and to refer suspect TB patients to the hospital for further investigation. TB patients were ill for between two and ten months before being diagnosed, during that time the patients first treated themselves with herbs and painkillers before going to traditional healers or the clinic. At the clinic patients were often incorrectly medicated for malaria. Failing to get better, patients then ‘ping-ponged’ between the various treatment options before being diagnosed; journeys back and forth from government health services were the most frequent. The case studies show how self treatments, visits to traditional healers and assumptions made at the clinic level can lead to delayed diagnosis.

Relocation was also a common feature of the therapeutic search in the period before TB was diagnosed – relocation leads to distress migration where married couples are forced to separate from their partners due to TB and families are broken down. Six patients relocated from the town to the village whilst sick and before diagnosis, all of who moved back to their mother’s household to be cared for. Women, especially mothers, are usually the primary caregivers. These are usually over stretched and burdened as they care for the sick. Further, many of the patients and their family members experienced different kinds of stigma.

Lastly, the most common theme in all the case studies is that TB patients and their primary caregivers were often unable to make a living during the diagnostic search and early in treatment. Illness can thus cause financial problem to the patients and the family. Although unable to earn a living, the household still had to pay for food and transport to the hospital. These expenditures eventually caused a strain on the families who started to sell of assets and later landed into debt. The above common themes and many more are discussed in the thesis with the aim of showing some of the problems that TB and HIV patients face in the search for treatment.

University of Cape Town

CHAPTER THREE

PEMBA/BATOKA – AN ENVIRONMENT WITH LIMITED SUPPORT

3.1 Introduction

"We must explore not only the life experiences of those sick with Tuberculosis, but also the larger social contexts in which they become infected, fall ill, and meet with a series of therapeutic misadventures leading to complications..." (Farmer 2000:183)

Inequality is an important aspect of poverty in Zambia. Since Independence, there have been high levels of inequality between urban and rural areas. Public services such as health and education frequently bypass the poor, and the services that are available are often under-funded, mismanaged, and capacity constrained - therefore of inferior quality (World Bank 2007). In Pemba/Batoka, people suffering from TB and living with HIV are reliant on four clinics for care. Pemba/Batoka site has an estimated population of 33520 (Kasiya 6981, Muzoka 7400, Pemba 7260 and Batoka 11879)²⁴.

Although the Zambian government has put in place health facilities such as clinics and hospitals, availability of the health facilities is not enough. The government has to ensure that the health facilities are accessible to all, especially those living in poverty. In Pemba/Batoka and other rural areas in Zambia, the clinics and hospitals are situated far from the people. No public transportation is provided that would make the health services accessible. Majority of the people walk 2-4 hours before they can get to the nearest health facility. Long trips by foot to the health centre are unrealistic for people who are not feeling well. They are also costly and enhance the risk of people stopping or not even initiating treatment. The distance to the health centres is therefore a hindrance to accessing

²⁴ Information about population was obtained from the clinics. They have records from the last census.

proper health treatment.

It is important to remember that availability and accessibility are not enough either - the health facilities have to be of good quality. Poor health infrastructure and lack of sufficient health personnel undermines the quality of health services that the government provides. In terms of infrastructure many clinics in the rural area lack well equipped laboratories. For instance in Pemba/Batoka only one clinic (Pemba Clinic) is a TB diagnostic centre. The other three clinics in the area are not yet TB diagnostic centres or ART delivery centres. They send sputum to Pemba Clinic or the hospital. This process leads to delay in diagnosis. In some cases, sputum bottles are lost during transportation and patients are sometimes asked to give more sputum. This some times causes patients to shun health centres.

Apart from laboratories, the clinics in rural areas are not big enough to accommodate all activities/programs at the clinic. For instance towards the end of the study, Pemba Clinic became an ART delivery centre, operating ART clinic and the general outpatient consultation were done simultaneously in the same room. Some patients accessing ART complained about confidentiality because they had to sit with other people from the same area.

In addition, the centre was understaffed hence; nurses had to attend to both the out patients and those who came to access ART services. This caused long queues, people waited for many hours and some patients were given fresh appointments – leading to late treatment and others gave up altogether. Further more the health staff was understandably feeling overstretched. Also, the overstretched staff had to deal with poor working conditions such as low level of pay. This is not only experienced by staff in Pemba but by staff in other parts of the country. Such conditions have forced for emigration of skilled persons from Zambia to other parts of the world. International permanent emigration of qualified persons entails a loss in a country's stock of human capital. Lack of human resources is the most crucial obstacle to proper health delivery in the country.

The above shortcomings of government have a great impact on the rural poor who cannot

afford to pay for private doctors. The rural poor solely rely on government services, thus it is important for government to remember that health services cannot just be accessible in the urban areas or to the rich but to all citizens.

Within the broad body of literature in anthropology grappling with HIV/AIDS and other infectious illness, the question of rural contexts in relation to health care is critical. The work of Paul Farmer (1999) in Haiti clearly demonstrates the relationship between structural inequality and infections and the prolonged delay of treatment in poor rural areas. Another reference to this literature is Ezekiel Kalipeni (2000: 969). His work on health and disease in Southern Africa highlights:

Governments in the region have attempted to provide biomedicine to everyone, focusing on hospitals, dispensaries and medical schools centred in urban areas to the neglect of rural areas... To obtain formal biomedical health care, rural residents have to travel long distances, sometimes on foot to urban centres where they have to endure a long wait before finally seeing a biomedical practitioner....Others give up.

These views contribute to a growing concern about the ways in which illness in rural areas of Sub Saharan Africa are intensified, prolonged, and often untreated due to poverty. The failure of government to address the health crisis compounds this concern. If the government's role is to provide social welfare support for the poor and marginal populations in the country, what happens when the government fails to provide adequate care for vulnerable populations such as people living with chronic TB and HIV?

Available literature suggests that, when the government fails, the non-governmental organisations (NGOs) fill in the gaps. In his discussion of NGOs, Thomas Kerbs (1987) states that NGOS are the most efficient and often the only effective means of promoting the interests of marginal populations in the developing countries because they are at the grassroots. Similarly an Associate Professor of Political Science and African Studies at Michigan State University, Michael Bratton (1989), points out that NGOs, deservedly or not, have gained a reputation as the leading practitioners of rural development in Africa.

Other literature on NGOs support the notion that NGOs are more effective than

government at alleviating poverty and hunger and can deal with disease better than national governments (CIDMAA 1992; Maher et al. 1997; Santosh 1999). The idealisation of NGOs by these analysts comes with the view that NGOs are everything that government is not: relatively flexible and open to innovation, more effective and faster at implementing efforts, and able to identify and respond to grass-roots needs (Chambers 1987; FAO 1994; Fisher 1997; Harding 1994). The belief is that NGOs and home-based organisations have the potential to reduce the burden on hospitals and the health centres, decrease costs to patients and their families, and improve adherence by making treatment more accessible.

My question is, in the context of my field site, do all NGOs live up to these expectations? To this end, this chapter argues that the rural poor who fall ill with TB have limited support from NGOs or extended family and are usually left isolated once they are diagnosed with TB because their space contracts to a point where it negatively affects them. Contracted space reduces the degree to which assistance can be shared across the dispersed network of kin and friends.

I begin the chapter by looking at existing NGOs in Pemba/Batoka and their challenges before moving on to discuss the extended family. I further explore experiences of the nine people suffering from TB and their caregivers in terms of how their space contracted once the patients were diagnosed with TB. I conclude by emphasising that the rural poor of Pemba/Batoka who fall ill with TB operate in an environment that has limited support.

3.2 NGO/Welfare support in the rural area of Pemba/Batoka

The term non-governmental organisation (NGO) is applied to groups providing social welfare services; development support or organizations; social action groups struggling for social justice and structural changes; as well as locally based groups that are not direct divisions of a national government (Fisher 1997; Weisgrau 1997). There are over fourteen NGOs and institutions working in Pemba/Batoka that deal in health related issues. Apart from the fourteen, each of the three clinics in the area has a registered home-based care

group. Entry into the home-based care group is free because this group is based on voluntary work in the community. In Pemba, there are three home-based caregiver groups, one under the Catholic Church, one under the clinic, and another under Linkages. Church Health Association of Zambia (CHAZ) funds the home-based caregiver group under the Catholic Church.

The function of the home-based caregivers is to visit families affected by TB, HIV or any chronic illness within the catchment area. Their primary role is to teach the affected families about the management of treatment of symptoms, and to give emotional support. They also encourage good hygiene and nutrition; and refer individuals to the clinic for further investigation, treatment and voluntary counselling and testing.

Although there were so many NGOs/institutions and home based caregivers in Pemba/Batoka, none of the nine TB patients recruited by the study ever received aid or received a visit from an NGO or a home based caregiver. The only institutions that visited the TB households were the church (whose members usually came to pray with the patient and the family) and the ZAMBART project counsellors. The most common church that visited was the Seventh Day Adventist church.

To demonstrate that there are a number of NGOs and welfare groups dealing in health issues in Pemba/Batoka but very little material support for the people, I will look at the work that was done by two of my colleagues during the course of my fieldwork. Levy Chilekwela and Susan M'lewa²⁵ held group discussions and interviews with young men, young women, older men, older women, people suffering from TB, people living with HIV and service providers. Service providers in this case were staff at the health centre that was connected to providing TB services through the clinic. The main objective of the group discussions and the interviews was to assess awareness, access, equity, and penetration of integrated TB and HIV services and household counselling in the community.

²⁵ Levy Chilikwela and Susan M'lewa are affiliated to ZAMBART under the Social Science department. This work is unpublished.

The findings of the group discussions are shown in Table One below. The table shows that services providers are more aware of the organisations that are dealing with HIV and TB but the target groups, that is people suffering from TB and PLWH, are not aware of these organisations. The only organisations that they are aware of are the clinic and ZAMBART/STAR. ZAMBART/STAR does not provide food aid but offers household counselling to the TB families.

Table 1: Awareness of NGO services

TB/ HIV Organization	Service Providers	Young Women	Young Men	Older Women	Older Men	TB Patients	PLWH
AED GAP Linkages	✓						
BIVChurch	✓						
BIZ AIDS				✓			
Catholic HBC	✓	✓		✓	✓		
CHAZ	✓			✓	✓		
Changes 2	✓						
Clinic	✓	✓	✓	✓	✓	✓	✓
CRAIDS	✓						
Kara	✓		✓	✓			
Planned Parenthood Association of Zambia	✓						
SAPEP		✓					
Seventh Day Adventist	✓		✓				
Women's Lobby Group	✓						
ZAMBART/STAR	✓	✓	✓	✓	✓	✓	✓

Note: The horizontal axis connotes awareness of a particular organization²⁶.

²⁶ African Economic Development Global Action Plan (AED GAP), Baptist International Vocal Church (BIV Church), Business and AIDS (BIZ AIDS), Catholic Home Based Care (Catholic HBC), Churches

I held focus group discussions with two home-based care groups in Pemba/Batoka in January 2007 - the home-based care group under the Catholic Church and the home-based care group under the clinic. This was done with the view to learning more about the operations of the groups and find answers as to why the local people were not benefiting from their services.

Both groups have over 100 registered members but very few are committed. The Catholic group has less than 30 committed members while the clinic has less than 20 committed members. Both groups face similar problems which inhibit them from visiting as many patients as they would like.

Firstly, it was observed that poverty was the main reason why the groups were failing to operate. It should be noted that these are voluntary groups, which do not give incentives to volunteers. Therefore, the majority of the members got tired of helping within the first month of joining. One participant from the clinic said, *"It usually does not make sense to go out in the field to help others when your own family has no food. Most people would rather go out to look for food for their own families than visit patients."*

Kironde and Kahirimbanyi (2002) had similar findings in a study carried out in Northern Cape Province, South Africa. In the study, Kironde and Kahirimbanyi explored factors that motivated lay volunteers to join TB control programmes in high burden but resource-limited settings. The study found attrition rates among volunteers to be high (22% had dropped out of the programme within one year of joining). 75% of the dropouts gave loss of interest and a desire for paid work as the reasons for leaving the TB programme.

It was also observed from the group discussions I held that the majority of the members earn a living by farming. Therefore, during the farming season, nearly all of them spend time in their fields rather than in the patients' homes.

The Catholic home-based care group owned a fundraising garden of vegetables in front of the house I shared with Florence. Florence and I became friends with the home-based care group members because they always collected water behind our house for watering the vegetables. The vegetables were grown by the group and then later sold at the market. Every morning we saw the same people watering the garden - the number never exceeded ten. This showed that only a few members were committed. During the farming season the number of people who used to water the crops was reduced. We stopped seeing some people and, when we asked, we were told that people were busy in the fields. In a study carried out in Malawi, Pauline Peters et al. (2007: 66) notes, "It is unrealistic to assume that rural residents who are normally fully occupied with farming, temporary labouring jobs, and other small-scale activities can allocate the requisite time and resources to running such businesses as volunteers." My point and Peters' point is that voluntarism in the rural areas towards managing HIV/AIDS and TB should be recognised as unrealistic. Diseases such as TB and HIV are too demanding to be left to the rural poor without the help of donors and government.

Secondly, both home-based care groups had transport problems. Pemba/Batoka area is largely made up of villages that are scattered, and it is not easy for the caregivers to walk the long distances. The clinic has two bicycles, but these are not enough to cater for all the members. No participants in the study had the privilege of home-based care groups bringing drugs to them. The participants had to walk long distances to the health centre to collect their TB drugs.

Thirdly, both groups complained of lack of food aid for the patients that they visited, especially for people suffering from TB and HIV who were on ARV treatment. *"I will talk*

from experience,” said one participant from the Catholic group who is on ARV treatment and was once a TB patient, *“When you are on TB drugs you need a lot of food because the drug makes you hungry and when you are on ARVs as well it becomes worse because you need the food not just because you are sick but because you need to stay healthy.”* Farmer also states that *“projects designed to treat tuberculosis among the very poor must include financial and nutritional assistance, for many of these patients develop reactivation tuberculosis in the setting of malnutrition or concurrent disease”* (1999:224). Patients that suffer from TB often request food aid.

“When you reach the household they will ask you what type of food you have brought for them or anything that you have taken for them,” said another participant from the Catholic group. Both groups revealed that they found it uncomfortable to visit patients when they had nothing to give. *“Sometimes we do all household chores if there is no one to do it so that the patient is left in a clean house. We also offer spiritual help to our patients. We pray for the patient and also encourage them to pray but that is not enough because they need food,”* explained one participant from the clinic.

The Catholic group offers food aid to some of its members. Each of the selected patients is given a 10kg bag of maize, 10kg beans, 10kg of cowpeas and 5kg of sun hemp. The food is donated each month by Churches Health Association of Zambia (CHAZ). During my stay in Pemba/Batoka I only came across one person who was benefiting from this service. She was a widow living in Pemba Town with two of her children. When I asked her how she found herself on the programme she told me that a friend of hers who belongs to the Catholic home-based care group introduced her to the group. Some people that I had spoken to claimed that home-based care members shared part of the aid and that is the reason why there was never enough for all the patients.

The Catholic home based caregivers on the other hand refuted these claims. They explained that the aid that they received from CHAZ was not enough and thus had applied to other “bigger” NGOs for assistance, but none had given a positive response. In analysing barriers to widespread non-governmental organisation involvement in

community-based tuberculosis treatment in South Africa, Kironde and Kahirimbanyi (2002) identified lack of adequate funding as the central issue that local NGOs were facing.

Apart from members of both groups not visiting the patients because of the problems mentioned above, it was also revealed that some patients did not want the home-based caregivers to visit them because most of the members lacked confidentiality. Some members discussed what the patient shared in confidence with other members of the community. *"Some patients do not want to be seen by HBC. They run away or chase us when we go there,"* one participant explained.

By the end of my fieldwork in Pemba/Batoka I came to learn that the majority of people working with local groups/institutions in Pemba/Batoka were willing to help. They were mainly concentrated in the town mainly due to a lack of transport, lack of food to give patients, and because they were looking after their own economic concerns. Therefore, they would not reach people with TB in the villages.

As noted earlier, poverty was a key factor because these volunteers were local people who were trying to fend for their own families. During the entire fieldwork period, I kept asking myself where the well-funded NGOs claiming to reach the grassroots were. Robinson seemed to answer my question: "Those large, influential and well funded NGOs may be able to concentrate resources in regions and sectors that might not be most important." (1993:8). In talking about the rural poor in Haiti and how those marginalised by poverty and discrimination need more and better health services, Farmer clearly writes, "Nothing is wrong with high-tech medicine, except that there isn't enough of it to go around. It is, in fact, concentrated in precisely those areas where it will have the most limited effects." (1999:14). For me, though talking about two different services - NGOs and clinics - both Robinson and Farmer show that, whether they have to do with health facilities or aid, resources are concentrated in urban areas and the rural poor are never or rarely reached.

As certain literature clearly illustrates, the claims that NGOs reach the poorest of the poor are often inaccurate (Edward and Hulme 1996; Fowler 1991; Tendler 1982; Wellard and Copestake 1993). In the case of Pemba/Batoka, by failing to provide food supplements, easier access to the health centre, or any form of income generating activities; both the NGOs and the government had failed to help the poor who greatly need their services for a better life.

The second question for me then is: When both the government and the NGOs fail to provide social welfare support for the marginal population, who takes up this role? Who in Pemba/Batoka provides aid and support for people suffering from TB and HIV/AIDS since the government and the NGOs cannot manage?

3.3 Role of extended family in managing TB

It is commonly assumed that the extended family in Africa provides a safety net for individuals in times of need. In her work on extended family, Mcgrath (1993:55) states that anthropologists have extensively studied kinship, marriage and family in Africa and they mostly conclude that “an institution at the core of African cultural patterns is the extended family”.

The United Nations Regional Adviser on Social Welfare Policy and Training, Economic Commission for Africa explained in 1972 (Shawky 1972: 4-5):

In rural Africa, the extended family and clan assume the responsibility for all services for their members, whether social or economic. People live in closely organized groups and willingly accept communal obligations for mutual support. The sick, the aged and children are all cared for by the extended family. (Cited in Seeley et al. 1993:117).

From the above, could we then say that the extended family takes up the role that the government and the NGOs have failed to take up in Pemba/Batoka? From my ten months

of fieldwork in Pemba/Batoka I can conclude, like the Panos Institute²⁷ (1990: 61), “The reliance on the extended family is overplayed.” My argument is that the extended family can only do so much. The care of people suffering from TB in Pemba/Batoka often fell on individuals with limited assistance from the extended family.

All the eight affected families informed us that they had close kin living near them but we observed that very few were visited. The more I spent time with the families I came to realise that the non-affected households had “more effective” networks than the affected. On every visit to both affected and non-affected households, I kept a record of who visited and the purpose of the visits. In comparison, affected households received fewer visits from extended family members. “*No one would like to visit a poor man,*” Sililo from non-affected household 5B once told me when I asked him why some households were visited more than others. From the discussion with Sililo and other informants, I learnt that people avoid households in need. In short, unlike the affected households, non-affected households were in a position to reciprocate.

The assistance offered by the extended family was limited because most of the close kin living in the same area were also poor subsistence farmers. Some would have loved to do more for their relatives but poverty was a limiting factor. When I spoke to Leo’s sister who frequently visited him and the mother, she explained, “*I wish I would do more to help my mother but I do not have much I also depend on my husband.*”

²⁷ Panos Institute is an organisation based in London, founded 20 years ago, to illuminate and provide insights from developing countries into issues facing people globally; and to stimulate informed, enlightened discussion around such issues. Panos’ job is to make the immensely complex issues facing developing countries accessible and understandable, to provide information that people can trust, and to open up opportunities for different perspectives to be heard. It tries to make sure that those who have most to win or lose from these debates – the most marginalised people in these societies – have their voices heard in the public arena.

Ankrah et al. (1991:971) record a similar situation in the study of impact of AIDS on the families of 24 people with AIDS in Kampala. They observe that, as the number of AIDS cases grow, “a crisis in functioning to meet the basic needs of sick and well members will occur in more and more families that cannot be addressed by the extended family”. Similarly findings by Seeley et al. (1993:122) suggest “populations under study often require material support, many families need moral and practical support, in the form of encouragement, reassurance and practical advice on how best to care, in order to provide adequate care for their sick members”. It is unrealistic to expect the extended family to offer these services and to cushion the impact of illness all the time.

The above discussion gives a general picture of how limited the support system was for the rural people suffering from TB. At this point I would like to concentrate on the limited support from the perspectives of the nine people suffering from TB by looking at the dynamics at play during the course of the illness episode - from onset of symptoms, to treatment seeking, and finally to the time at which the patient is diagnosed with TB.

3.4 TB and SPACE

“One of the key analytic challenges to understanding possible changes and differences is that of determining what the household affected by death and illness would have been doing if they had not had such traumatic events, to thereby understand the impact of the events.” (Donovan and Bailey 2006:110)

To understand how the lives of nine people and their families had changed due to illness I asked questions such as: How did you earn a living before the illness? What do you do now? Who were your friends before TB illness? Who are your friends now? What has changed?

The answers I got from these discussions, as well as my observations, made me realise that the experience of illness recounted by the patients and family members tells a story of

how social and physical space expands and contracts when a person has TB. To discuss the social and physical space of the nine patients, two themes - mobility and boundaries - will be explored.

3.4.1 Mobility

Mobility measures migration within a population. It is commonly used in demography and human geography. Mobility in this thesis implies the movement of people from one point to another and includes people who, in a specified period, have not moved or have moved from one home to another. It will also apply to routine daily mobility and how this changes during TB illness. The onset of symptoms often brings about mobility because at that point the patient moves from one point to another in search of treatment.

Examining pluralistic health care within societies, Helman (2000:43) states that there are three structural domains of health care society. The first is the popular sector- the lay, non-professional, non-specialist domain of society. The popular sector is made up of self treatment which Helman (2000: 43) defines as “advice or treatment given by a relative, friend, neighbour or workmate.” The second is the folk sector- largely found in non-western societies, healing which is sacred or secular, or a mixture of the two. This varies according to society some examples of these include herbalists, spiritual healers, midwives. The third sector is the professional sector which comprises the organized, legally-sanctioned healing professions, such as modern scientific medicine. Helman further argues that ill people frequently utilise several different types of healing at the same time, or in sequence. “This may be done on the pragmatic basis that ‘two or more heads are better than one’ (ibid: 53)”. My observation during fieldwork revealed that all the nine people had utilised at least two or all three sectors during treatment seeking.

All the nine started with self-treatment and five²⁸ out of nine people visited traditional healers. Visits to the clinics also added to increased mobility for the patients. All the nine

²⁸ Rocky, Alex, Leo, Beatrice and Mukupa.

visited a hospital outside their village or town before they were finally diagnosed with TB. They were also moving from one household to another in search of care. As the symptoms progressed and the patient became weaker, the patient was sometimes forced to relocate, leaving behind a home, family members, friends and employment to go and settle in a place where they thought they would get assistance.

Six out of nine moved from their homes in town to the village for care, support and food. Similar findings by Bond (2006:192) report that the sick move back to the village due to close family ties and the tradition of care in the village. She further states, "The irony of this trend is that, in the face of limited food and services and support, people living with HIV and AIDS will die quicker in the village." Thus, one negative impact of TB is on the mobility of the patient who is forced to leave their regular home and work to settle in the village, which has limited resources and opportunities. Innocent, who was living in the village because of his illness, remembered the opportunities he had left in Kitwe Town.

"There are a lot of opportunities for piecework unlike here. In the village, the only piecework you can find is working in someone's field. In Kitwe you can wash cars, help to carry people's things at the station or bus stop. You can even work at a bar, during the night you help the bar tender to pick bottles. Life is tough in the village."

Although they had relocated from their original homes to other homes for care, Beatrice, Leo and Innocent kept moving between houses in search of a better place than the one they first moved to. For Beatrice, a better place meant a place where she would find peace, a place free of her co-wife; for Leo, a better place was a place where he was free from his mother and a place where he would find food. Innocent, too, kept moving from his mother's house to his sister and father's houses in search of food. Therefore, even after TB diagnosis, mobility still continued for these three TB patients.

3.4.2 Boundaries

Once a person is finally diagnosed with TB there seems to be an invisible boundary around them, especially for those who are bedridden. Their space slowly starts to contract and they are unable to perform their normal functions as they used to before the illness. To have a better understanding of this, I will concentrate on two cases: Rocky and Molly.

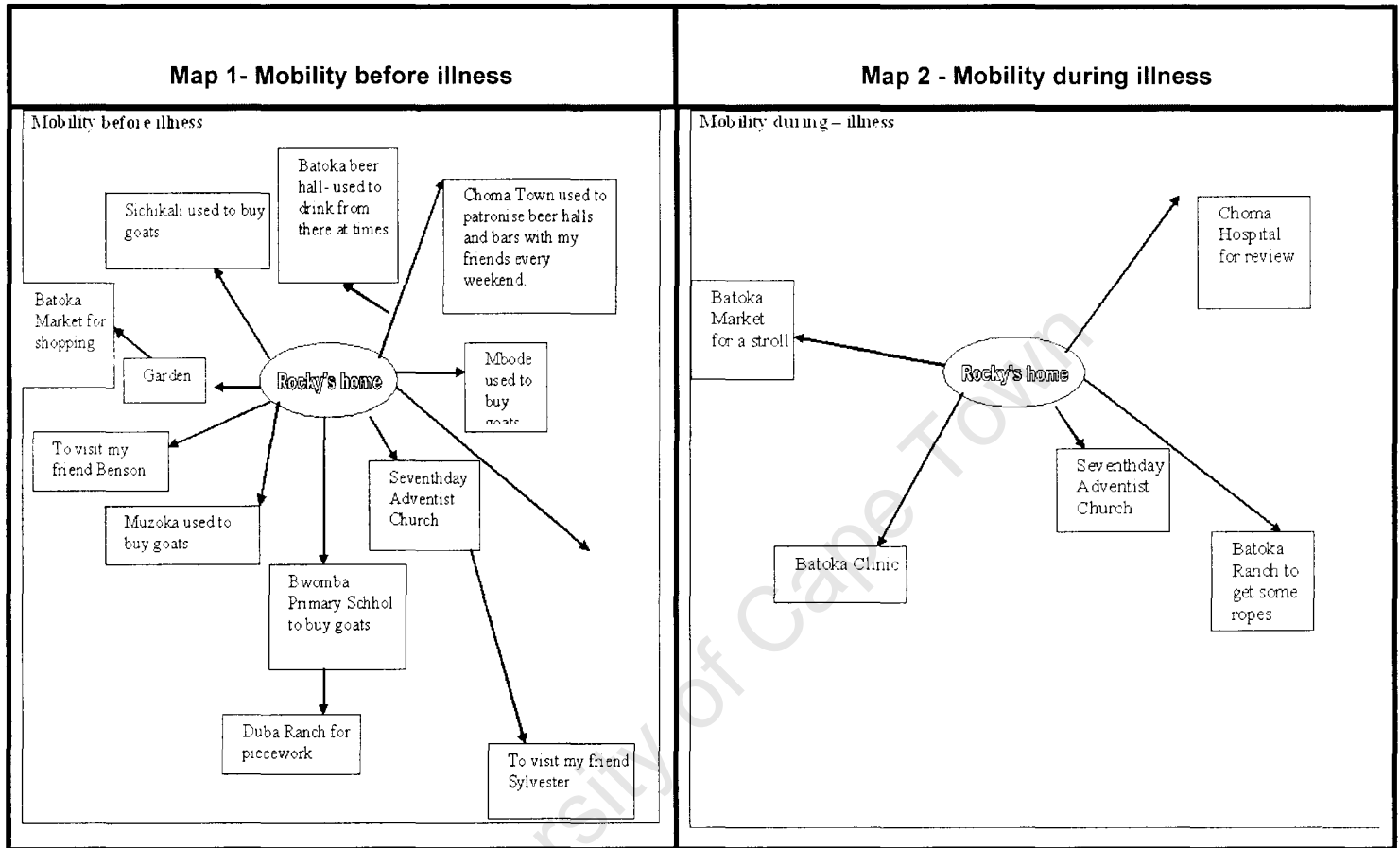
When I met Rocky during the first month of TB diagnosis, his physical space was very limited. His mobility was limited to the house, toilet, bathroom, and under a tree where he used to lie for fresh air. At this stage, he could not even move unaided. His mother used to feed him and help him move from his house to outside. His wife used to take him to the bathroom and toilet. Socially, he had no friends visiting him and he could not visit them because he was weak. Thus, all that Rocky did at that time was eat and sleep.

After two months, his mobility expanded a bit. Though weak, he could walk on his own unaided by his wife or his mother. At this stage, Rocky could walk around the house, take a walk to the market, which was about a kilometre away, and eat his meals with no help.

It was during this time that I sat with Rocky, gave him a pen and two pages, and asked him to map his social space. Rocky had to map all the places he visited before the onset of symptoms on one page and on another the places he visited after the illness. Drawing the maps with Rocky was interesting because it really helped to bring out all the places that Rocky visited before the illness. He was also amazed at how his movements had changed since having TB.

From the first map it is evident that Rocky was far more mobile (Fig.15). Rocky used to go to work every day from Monday to Friday at the ranch. In the evenings, he used to go to the local bar for beer. Over weekends, he used to visit bars even as far as Choma, 40kms from his own town of Batoka. This was an occasion to be with his friends and interact outside of work.

Figure 15: Illustration of Rocky's changes in mobility before and during illness.



Rocky also used to assist his mother with buying goats. These goats were mainly bought from Muzoka, Sichikali and Bbombo primary school. All these three places are far away from his home in Batoka, but he used to walk to these distant places to conduct the goat business because at that time his physical strength allowed him to do so, thus expanding his space.

Similarly, I gave Molly a pen and two pages. After she was done with the mapping (see Fig.16), I asked her to compare her first map to the second map and tell me what she could see. After staring at the maps for a few minutes, Molly observed that her life had changed from the time she fell ill. She said, *"My life has changed. I stay more at home unlike the time when I was well. Those days I used to move around but now I cannot. In addition, this*

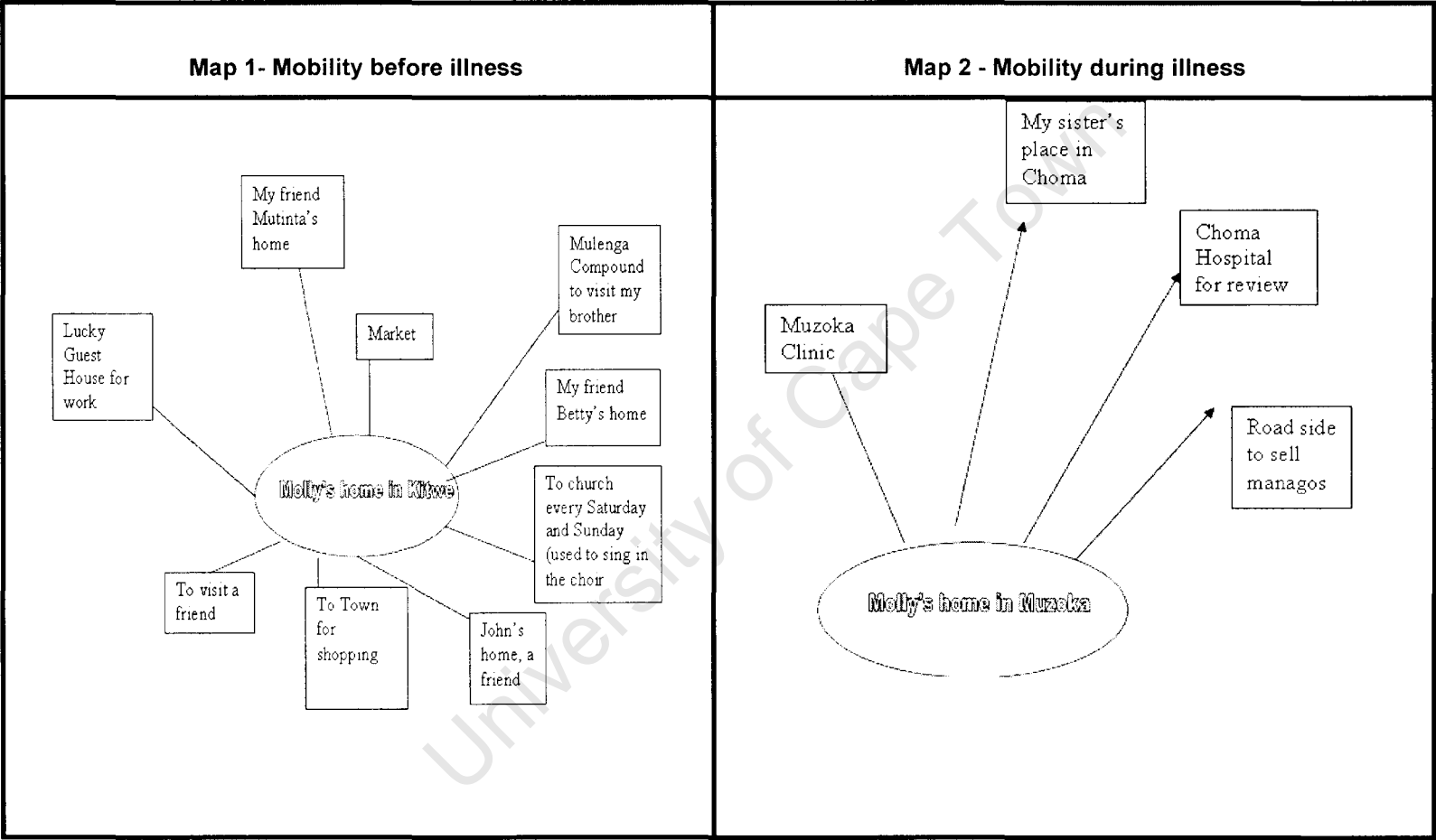
is a new environment for me. Even if I want to go and visit, I cannot because I hardly know anyone. I wish I could go to church and sing but I am unable because of my illness."

She wished she could do some of the activities that she did before the illness. When a similar exercise was done with Molly's brother, Innocent, it had a different meaning, for him, the first map showed happy times while the second map showed sad times. *"Those days I was everywhere, I was happy but now I am at home. I spend more time at home or the hospital, I have no social life."*

A conversation of a similar nature and the same exercise was performed with the rest of the nine people suffering from TB²⁹. Findings showed that Molly and Rocky's experience of mobility was typical in all nine patients, and a similar pattern was seen in all their maps. All nine people reported having had a wide network of friends before the illness. They had friends who they used to visit and who in turn visited them. However, after being diagnosed with TB, they lost almost all contact with friends. There seemed to be a boundary that restricted their space to the family members whom they were living with.

²⁹ This exercise was not performed with Alex because he died before he gained enough energy to draw. All information collected on his mobility was done so through conversations.

Figure 16: Illustration of Molly’s changes in mobility before and during illness



Of course, part of the reason that the six patients who had moved to the village had few friends was because they were in a new environment. This applied to Mukupa especially, because she was in a place she had never even visited before. The other five had a few friends in the village because they had lived in the village before moving to town for work opportunities, but they still had no friends visiting them.

In addition to lost friends, they also lost a chance to visit other family members other than the ones they lived with. The first map for Beatrice, Leo, Mukupa, Victor and Yvonne showed that, before the illness, they used to visit family members living either within or outside town, while their second maps showed that only Beatrice and Leo managed to make a visit to relatives after they had been diagnosed with TB and this was in order to be assisted. The rest had not gone to visit family members.

Therefore, due to TB, their social space contracted, and they interacted more with the family members within the household than with outsiders. This contraction affected the patients and their families negatively because it reduced the degree to which assistance could be shared across the dispersed network of kin and friends. Furthermore, it contributed to food insecurity because the affected households became more or less socially and physically isolated and, when they experienced food problems, there was a limited network to turn to.

From the maps, it was also possible to tell that the nine people had experienced a loss in economic opportunities. All the first maps show some form of economic activity. For example, Rocky's map shows that before the illness, he used to go to the ranch for work and was involved in a goat business. Molly also used to work at a guesthouse, but the second map shows that this was given up.

The maps also showed how the social activities of the patients changed over time. The maps drawn by the five men showed that before illness they all used to visit many bars,

taverns and markets, which were possible sources of infection. Literature (Classen et al. 1999; Graviss et al. 2001; Mangura 1998) on TB transmission shows that a significant amount of transmission takes place outside the household. The literature reveals that public gathering places are significant in facilitating the transmission of TB; and suggests that informal drinking places such as bars; taverns and shebeens pose the highest TB transmission risk. The literature further points out that many gathering places such as churches; markets and bus stations carry a significant risk of TB.

The maps drawn by the women, on the other hand, showed that they used to go out to the market for business and they also used to go to church. These social activities changed when the patients were diagnosed with TB. The second maps for the men showed a change in activity where they moved from visiting bars and taverns to spending the whole day at home. Some of the men began to attend church. The women also recorded a change in activities. Before her illness, Molly used to go to church and she was a member of the choir, but due to TB she could not sing in the choir.

To find out more about the activities that the nine people were engaging in, a record of daily activities was kept by all the nine patients on each visit. Each person was asked to give a full account of what s/he did the previous day starting from the time the person woke up to the time the person went to bed. A similar exercise was performed with adult members in the comparative household. Table 2 show one of Yvonne's activity charts two months after diagnosis and Table 3 show an activity chart of one of the adults in the comparative household.

Table 2: Yvonne's daily activity chart

Name Yvonne	Activity (describe)	Time begun	Time ended
	Wake up	06:00	
	Washed clothes	06:00	07:00
	Bathed and ate breakfast	07:00	08:30
	Rested under a tree	08:30	09:00
	Kept my daughter company as she worked in the garden	09:00	12:00
	Helped my daughter prepare lunch	12:00	13:00
	Ate lunch	13:00	13:30
	Washed plates	13:30	14:00
	Rested	14:00	19:00
	Eat supper	19:00	19:30
	Chat with my children	19:30	20:00
	Went to bed	20:00	

Similar daily activity charts from the rest of the participants show a loss in productive activities as compared to their adult counterparts in the comparative household. Take for instance Yvonne's and Hope's charts, the charts show that - unlike Hope who was able to go to the field to work - Yvonne only went to the field to sit and chat with her daughter who was working. Hope also did more household chores.

Table 3: Hope's daily activity chart

Name - Hope (comparative to Yvonne)	Activity (describe)	Time begun	Time ended
	Clean the house and surroundings	06:00	08:00
	Went to the field	08:00	11:00
	Cooked lunch, ate and cleaned up	11:00	14:00
	Went to the field	14:00	17:00
	Cooked supper, ate and washed the dishes	17:00	19:00
	Went to take a bath	19:00	19:15
	Sat to chat with other household members	20:00	22:00
	Slept	22:00	

Alex's chart too showed that there was a loss in productive activities (See Table 4). In fact, Alex's chart revealed that his only activities were to sleep, eat and bath, while Jordan's chart, comparative adult (see Table 5), showed that he was involved in productive activities and had a social life too.

From Jordan's chart, we can see that Jordan had been out in the field and had been out on drinking spree. When Alex's first activity chart was done, he had not been up from his bed for two weeks and had developed bedsores and swollen legs. He was very ill and could not stand on his own or bath himself.

Table 4: Alex's daily activity chart

Name of patient - Alex	Activity (describe)	Time begun	Time ended
	Bed		
	Ate breakfast	07:00	
	Bed		
	Eat	10:00	
	Bed		
	Ate Lunch	12:00	
	Bed		
	Ate	15:20	
	Bed		
	Ate supper	18:00	
	Bed		

Table 5: Jordan's daily activity chart

Name - Jordan(comparative to Alex)	Activity (describe)	Time begun	Time ended
	Planting in the field	04:00	12:00
	Bath	13:00	13:30
	Lunch	14:00	14:30
	Drink some beer	Afternoon	Evening
	Supper	18:00	
	Bedtime	20:00	

The daily activity charts also revealed that all the four women were able to engage in household chores, such as cooking and sweeping the compound surroundings, after three months of being diagnosed with TB, but they were still not able to do heavy chores like drawing water or farming. Similarly, the men were not able to engage in any heavy activities such as farming.

From the above discussion, we have seen how the nine people suffering from TB lost friends and stopped visiting almost all the places they used to visit before TB, but this does not mean they were completely isolated. Due to their illness, and in the search of treatment, they met other people and encountered other institutions such as the clinic and the clinic staff - subsequently developing new associations and new networks. When we look at the first maps, we see no visit to the clinic or hospital by Molly or Rocky, while both second maps show that they had paid visits to the clinic or hospital. They further found themselves at the TB corner³⁰ and through visits to the TB corner; they developed new friendships and met new people.

Apart from the clinic and clinic staff, ZAMBART Project members visited all the nine people, who were offered counselling. Through this contact they came to meet new people that they would not have met if they were not suffering from TB. From the counselling sessions, they gained more knowledge about TB and HIV and received additional support that some members in the community were not privileged to have. They also made new associations through contact with Florence and I.

In addition, visits from church members brought new associations for the nine people. Apart from Rocky, whose family had been banned from attending church services because they had been visiting traditional healers, and Molly, who did not want to see church members at her home but preferred to pray alone, the rest of the my participants reported

³⁰ The TB corner is a section at the clinic where TB drugs are administered to TB patients. The nurse on duty on also gives health talks to TB patients on how best they can care for themselves and others around them.

having received visits from members of their congregation depending on their church affiliations.

Although the nine people had developed new associations, these new associations would only assist them with health care and not economically. Staff at the health centres could only offer medicines and knowledge about the illness, but did not give out food supplements. Secondly, ZAMBART and I were carrying out research, which did not offer financial or food aid; thus the patients and their families still lacked assistance in terms of food and capital.

3.4.2.1 Boundaries for other members of the family in the affected household

Other members of the affected households, especially the caregivers, were slowly reducing their mobility. When we administered the daily activities chart to the caregivers (see examples in Table 6 and Table 7), we found that the caregivers usually spent time at home with the patients; and when they moved, their movements were always conducted to ask for some assistance, collect TB drugs for the patient, or look for food.

When we compared the caregivers' movements to the comparative households', we found that the adult members in the comparative households visited a wide range of places and engaged in social activities, unlike the caregivers. For instance, when we compare Rita's and Tamara's charts we see that, unlike Tamara's chart, Rita's chart shows that - apart from household chores - she also went to church for choir practice. In addition, when I first met Rocky, his mother used to go to Lusaka for goat business but slowly started reducing her trips and, by the end of my fieldwork period, she had completely stopped the business.

Table 6: Tamara's daily activity chart –caregiver to Victor

Name – Tamara (wife and caregiver to Victor)	Activity (describe)	Time begun	Time ended
	Wake up and started cleaning the house and yard	06:00	07:00
	Went to the field	07:00	10:00
	Picked some vegetables for lunch and I started preparing lunch	10:00	12:00
	Cleaned the plates then I went to herd the goats until my children came back from school	12:00	16:00
	Started looking for something to cook and then I prepared supper.	16:00	19:00
	Bed time	20:00	

Table 7: Rita's daily activity chart-comparative to Tamara

Name- Rita(comparative to Tamara)	Activity (describe)	Time begun	Time ended
	Field	05:00	12:00
	Cooked lunch	12:00	13:00
	Rested	13:00	13:00
	Went to church for choir practice	14:00	16:00
	Cooked supper	16:30	18:00
	Sat to chat with family	19:00	21:00
	Went to sleep	21:00	

The combination of the patients' incapacitation and caregivers' reduction in economic task resulted in a decrease in household income. Due to his illness Victor's income reduced

from about K250 000 to K30 000 a month. *“Before my illness I used to take up three contracts at a time because I was fast. In a month I used to make good money, K200 000 to feed and dress my family. Nowadays I only work on some days and on those days I work up to 12:00 hours because my body is too weak.”*

Apart from Victor who lost part of his monthly income, the rest reported to have lost their income completely because they were bedridden for some time. Many studies have been done to show how illness can cause a loss of income. In a study in Bangladesh on the implications for women and children when the principle household earner falls ill, Pryer (1989) estimated that afflicted households lost 74% of monthly incomes. In Uganda, Saunderson (1995) reports that 80% of wage earners had stopped work because of illness and the average income lost from inability to work was \$161. In Nepal, Sauerborn (1996) estimated that the income lost amounted to 70% of total monthly income. Other literature on impact of ill health on poor families shows that illness causes households to lose income (Barnett and Whiteside 2006; Dogra 1988; Lasker 1981).

In addition to lost income, friends were lost. Like the patients, two caregivers found their friends stopped visiting. Although she still used to visit her relatives who lived 100km away for assistance, Rocky’s mother was never visited and she never visited any friends. Molly and Innocent’s mother also lost most of her friends when her children were diagnosed with TB. Her friends stopped visiting her because they were unhappy that she was associating with the ZAMBART staff, who they claimed were Satanist.

Nevertheless, when the patients were much better, friends started visiting again. Six of the caregivers had friends who used to visit them at this stage and sometimes they used to bring local sweet beer, *chibwantu*, for the patients. However, the caregivers recorded no social visit to their friends unless when they went to borrow money or to ask for assistance. Thus, the caregivers too reported diminished mobility and had invisible boundaries around their homes preventing them moving far away from the patients.

Finally, it was not only the patients and caregivers that experienced contracted space, but

some of the children in the affected households could not visit their friends in the neighbourhood (See Chapter Five), thus this left them isolated because they too had invisible boundaries restricting where they could and could not go.

In conclusion, it is evident from the above that, before illness and during the onset of symptoms, the space of nine people suffering from TB does expand and their mobility increases because they move from one point to another. What I have tried to show in this chapter is that, in the rural area, the people who suffer from TB can sometimes have limited help from NGOs, extended families and friends and, due to their illness, their space reduces to a degree such that assistance cannot be shared across the dispersed network of kin and friends. Although all the nine people did develop new associations, the new associations could only help socially and not in terms of food. Therefore, in the chapters that follow it is important to understand the context in which the nine people and their families were operating. There was no help from government or NGOs, and their space had contracted leading to diminished mobility, which in turn led to decreased economic resources and eventually to an increased insecurity around food.

CHAPTER FOUR

THE ECONOMIC IMPACT OF TB AND TB/HIV CO- INFECTION ON HOUSEHOLDS

4.1 Introduction

"My biggest problem is that I have no money to use. The rains are about to start but I cannot farm and this means that my children will starve next year. If I had money, I would have paid other people to farm for me so that by the time I get well my children will have something to eat. I feel very bad because my family is now affected." (Alex, October 2006)

"My life has changed! It has changed so much because I cannot do the business I used to. When my mother was not suffering from TB I used to sell vegetables and fruit at the market but after she fell ill with TB I started spending my time with her and I found myself doing more piece work." (Yvonne's daughter, January 2007)

The poor are vulnerable to further deprivation due to the lack of "buffers" or extra resources that they are able to call upon when in need (Chambers 1989). Having established the limited support of poor households affected by TB, this chapter dwells on the costs and the consequences of ill health especially in a context where caring for the patient is left to the family. Drawing on a wide range of literature, (Ahlburg 2000; Barnett and Blaikie 1992; Barnett and Whiteside 2002; Chambers 1989; Corbett et al. 2003; De Waal 1989; Devereux and Maxwell 2001; Farmer 1999; Helman 2007; Pottier 1999; Pryer 1989; Scheper-Hughes 1992; Watson and Caldwell 2005), I try to show the many problems that the households faced in trying to deal with TB, and sometimes with both TB and HIV.

Firstly it should be noted that, when an adult member of a household is suffering from TB, there are several crises happening at the same time. There is the health crisis itself; then an economic crisis because the sources of income are lost, which in turn leads to lack of food;

and then there is also a social crisis because that person and the rest of his or her family might face stigma (see Chapter Five). Swift (1989), notes that a health crisis and food crisis are closely related, and indeed a more general crisis is involved - the social and the economic crisis. Although he points out that the order in which these occur has been clearly understood, my own observations are that they all happen at the same time – there is a web of crises, with so much happening at once. People complained about the illness, lack of food, lack of money, feeling isolated and sometimes depressed.

This chapter is divided into three sections. The main argument in the first section is that TB compounds food insecurity - TB can cause loss of production when farming is neglected at the expense of caring for the patient. The first section starts with the definition of food security. Then moves on to give a brief overview of agriculture production of Pemba/Batoka in 2005/2006 and 2006/2007 farming seasons because I started my fieldwork on the end of the 2005/6 season and saw the households through 2006/2007 farming season up until July. The section then discusses the impact of TB on the food security of poor households by comparing affected households with non-affected households. In the same section the chapter explores the eating patterns of both affected and non-affected households. Lastly, it looks at the demands that patients put on households for special foods and how this compounds food insecurity.

The second section of the chapter looks at the high cost of TB illness and argues that, if people are co-infected with both TB and HIV, costs are increased as people access ARV services. Drawing on Rugalema (2000), the last section of the chapter tries to show how households affected by TB escape high costs of illness by borrowing and disposing of assets. It consequently shows that the actions of borrowing and selling of assets has major consequence because no investment takes place.

4.2 Food security issues in households affected by TB

“Food is essential to life and must enter our bodies daily in substantial amounts if we are to live,” (Counihan 1999:7). It is a basic need because there is no more absolute sign of powerlessness than hunger; it can lead to violence (Scheper-Hughes 1992:211) and it can lead to death. That is why “those who suffer from chronic deprivations are, not surprisingly, nervous and insecure” (ibid 1992:169). Considering the importance of food, anthropologists and other social scientists have done a considerable amount of research on food. They have clearly stated that food consumption habits are not simply tied to biological needs but serve to mark boundaries between cultures, social classes, genders, geographic regions, nations, life cycle stages, religions and occupations; and to distinguish rituals, traditions, festivals, seasons and times of day (Adams 1990; Counihan 1999; Counihan et al 1997; Helman 2007; Lupton 1996; Reiter 1991).

Meanwhile, more research needs to be conducted on the absence of food in everyday lives of the people (Watson and Caldwell 2005). Following the path of anthropologists who have focused on the food shortages in third world countries (De Waal 1989; Pottier 1991, 1996, 1999; Scheper-Hughes 1992; Vaughan 1987), this section of the chapter contributes to the growing literature of anthropology on food. The section argues that, because of illness, the rural poor who are affected by TB and HIV become critically food insecure.

By definition, food security is broad and complex because it focuses on a range of physical, socio economic and biological factors. Therefore as a concept, food security does not have one agreed definition; but is often used broadly to mean a situation in which people experience continuity of food supply, or the methods by which this aim is achieved. Devereux and Maxwell (2001: 15-16) offers a wide range of definitions (32) since the World Food Conference in 1974 to 1991.

Availability at all times of adequate world supplies of basic food-stuffs...to sustain a steady expansion of food....and to offset fluctuations in production and prices. (UN 1975, cited in Devereux and Maxwell 2001)

The viability of the household as a productive and reproductive unit (not) threatened by

food shortage. (Frankenberger and Goldstein 1991, cited in Devereux and Maxwell 2001)

What is striking about these definitions and in Maxwell's analysis is that there has been a paradigm shift from looking at food security issues from global and national (1975) to focusing on the household (1991). In fact, "anthropology has been at the forefront of debate as, when the (so called) international community discovered how 'the household' needed to come into stronger focus in discussions of food security" (Pottier 1999:8).

I think that we should go beyond the household and dwell on the individual too. It takes several individuals to make up a household, thus it becomes important to focus on the smallest unit in the global. My argument is that intra-household relationships of food and the individual should also be explored when dealing with food security issues of households affected by ill health, because some household members can be neglected at the expense of the patient. Barnett and Whiteside (2002) and Gillespie and Kadiyala (2005) note that household-level analyses also fail to capture the complex interactions and relations between and within households. Therefore, I advocate for a more subjective analysis of what individuals eat and how they feel about what they eat. This said, for the purpose of this work, I used the FAO definition of food security that recognises the individual and also, as Pottier notes, recognises that "poverty is the major cause of food insecurity and that eradication of poverty is essential to improve access to food" (1999:13).

Food security, at the individual, household, national, regional and global levels....exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life. (FAO 1996:3)

4.2.1 Overview of the farming seasons of 2005/2006 and 2006/2007

"The good harvest from the 2005/006 production season has generally increased the supply of food and improved food access for both urban and rural households," reported the Zambia Vulnerability Assessment Committee in July 2006. There was a bumper harvest in 2005/2006 unlike in 2006/2007. In 2006/2007 farming season, Zambia generally experienced exceptionally high rainfall since early January, provoking flooding in many

parts of the country. A joint FAO/WFP Crop and Food Supply Assessment Mission visited the country from 25 April to 18 May 2007 and estimated total maize production for 2007 was at 799 000 tones, some 46% lower than the previous year, and 13% lower than the year before (FAO 2007). Primary factors responsible for this decline were adverse weather, severe economic constraints leading to shortages of key farming inputs³¹, deteriorating infrastructure - especially for irrigation – and, most importantly, financially uneconomical prices for most of the government-controlled crops.

In Pemba, 2006/2007 season's rainfall pattern was characterised by below-average (800mm) quantities and a very poor and erratic distribution. But the months of December, February, and the beginning of March had a good amount of rainfall. The area planted with maize was slightly reduced, despite many farmers' intentions to plant more (FAO 2007). Factors contributing to the reduction in area included the late start to the rains, the short period of good planting rains, inadequate drought power, and delays in accessing inputs. In addition, the inputs delivered were not sufficient. The agriculture extension officer³² explained that government had only supplied 200 bags of seed for 200000 farmers. Thus, most of the farmers used recycled seed and there was only a minimal use of fertiliser because this too was delayed. Many farmers could not afford to buy from the shop because it was expensive (K120 000 per 50kg bag). *"Only those farmers who were able to plant their maize by the end of October obtained a satisfactory crop. Generally 2006/2007 farming season had low yields of 35 by 50 bags per hectare as compared to the 60 to 100 by 50 kg bags of last year,"* the agricultural extension officer said. He further pointed out that overall the food situation was not bad because about 50% of the households were food secure and were likely to have food by March 2008.

From the above it is easy to see that compared to 2005/2006, 2006/2007 farming season was not good. Hence, in my discussion that follows others might argue with my findings because a reduction in household production could not have been entirely due to illness,

³¹ inputs means resources that one needs to be able to farm like seed and fertiliser

³² Information from the agriculture extension officer was obtained in July and August of 2007. He greatly contributed to gathering information on the farming seasons of Pemba/Batoka.

but also due to additional factors.

4.2.2 Food production of the households

"Farming is a problem; because I spend all the time looking after the patients, my farming has become so poor," lamented Innocent and Molly's mother. She and her husband had, within a space of two years, lost a daughter in-law and a granddaughter to HIV-related illness. The illness and death of the two drained the family economically and, before they could fully recover, Molly and Innocent fell ill too. This situation - where time was spent on caring for the patient instead of on planting - was a common trend amongst these rural households. Six out of the seven affected households complained of having less time on their hands to work in the fields. Mukupa's family did not complain because there were many adults in the household. When the grandmother was looking after Mukupa, the rest of the household was out planting, thus they shared the burden of caring.

The impact of illness on crop production relates to a reduction in land use, a decline in crop yields and a decline in the range of crops grown (Barnett and Whiteside 2002, FAO 1996, Gillespie and Kadiyala 2005). The reduction in land use is attributed to a number of factors which occur as a direct result of illness, such as fewer family members being available to work in the fields, and thus a reduction in the amount of land that can be cultivated.

During the farming season, it was difficult to find non-affected households at home, especially in the period between December and February when they spent the whole day in the field, only breaking off for an hour for lunch. To spend some time with them, Florence and I followed them in their field. Affected households on the other hand were usually at home during this period. The only time we did not find them there was when they had gone to the clinic for review or to other people's farms to do piecework. Alex's brother once said, *"I am disturbed, all my programmes are disturbed, I fear going far, I am the only older man around and if anything happens to him I have to take charge."* The fear of leaving the patient alone made most of the caregivers stay close to the patient most of the

time, and this in turn affected farming. A similar study done in Tanzania (Mutangadura 2000) showed that a woman whose husband was sick was likely to spend 45% less time on agriculture than if the husband were healthy. Another study conducted in Ethiopia showed the reduction in agricultural labour time: the number of hours per week in agriculture fell from 33.6 hours in non-afflicted households to between 11 and 16 hours in afflicted households (Black-Michaud, 1997, cited in UN 2004).

In cases where either the caregiver or one of the household members planted crops, it was always done right next to the compound so that they did not have to move far from the patient. This was mainly observed in Beatrice, Rocky, Leo and Molly's households. The other observation was that, in non-affected households, the whole family went out to the fields to work; while in the affected household, it was usually one person who did the planting, which led to only a small area being cultivated.

In relation to planting a small area, many households in Pemba/Batoka plant their maize on an anthill (*ciduli*) because it is believed that these are more fertile than the lower-lying land. Therefore, households plant on both anthills and lower-lying land. With no money to buy fertiliser and very little time on their hands, Rocky's household planted their entire crop on four anthills that surrounded their compound. Indeed their maize was healthy but their harvest was not much.

Apart from spending less time in the field due to caring for the patient, four affected households spent time working in other people's fields. According to participants in four focus group discussions I conducted with elderly people in the community and with community health workers, working in other people's fields is a local indicator of poverty (also see Milimo 1994). Production was also adversely affected due to the fact that the affected households spent more time working for better-off households. "*My husband is doing piece work in other people's fields. When it is this time of year we raise money by doing piece work in other people's fields,*" Enesia responded when I asked her where her husband was. The households went to do piecework in better-off households for "fast

cash”, though it was usually very little ranging between K2000 and K5000 (a dollar or less). However, in most cases they were paid in kind (maize meal or any food). The search for cash for food and transport money to the hospital by affected households added to food insecurity because their own farm production was neglected.

During the start of my fieldwork in both affected and non-affected households I recorded all the maize harvested in the 2005/2006 farming season. This was done by conducting interviews with the heads of the households. Each head was asked how much he/she had harvested that year and then all butalas for all households were checked to establish how much maize the household had. Then, during the course of fieldwork, I also recorded all maize harvested in the 2006/2007 farming season³³. It was easy for me to establish how much (too little or too much in relation to other people in the community) the household had planted, were they got the seed, fertilizer and how much they had harvested because I lived in Pemba/Pemba through out 2006/2007 farming season. I also took photos of the fields for both comparative and affected households in order for me to have a fresh memory of how their fields looked from start of planting till harvest time (see figures 17 and 18 for examples of photos).

However I must point out that it is not easy as a student researcher to measure a household's exact harvest due to the following reasons. Firstly, as the produce ripens the family starts to eat such that when they finally harvest all produce from the field, some of it would have been eaten. Secondly, I did not have a standard or systematic way of measuring maize harvested; all produce was measured according to the local ways of measuring i.e. using ox-charts or 50kg bags. Therefore, I would not carry out the measurements myself but depended heavily on participant observations³⁴. I had a task of spending as much time as I would with the households during harvest time so as to record everything I could.

³³ Note that households generally have one harvest per year and use the maize over the whole year.

³⁴ Took part in harvesting and helped count how much was harvested.

Figure 17: Molly and Innocent's parent's field



Figure 18: Comparative household's field



the food. The question on my mind is how are they going to survive? If they were like other normal children I would not worry so much, but all my children are like babies."

Table 8: Household production before and after TB

Affected Household	2005/2006 harvest	2006/2007 harvest
Rocky 1A	Eight 50kg bags	Two 90kg bags
Alex 2A	3 ox-carts plus six 90kg bags	2 ox-carts
Molly and Innocent 3A	3 ox-carts	½ ox-cart
Leo 4A	1 ox-cart	Nil
Beatrice 5A	Nil	Nil
Mukupa 6A	4 ox-carts	4 ox-carts
Victor 7A	3 ½ ox-carts	2 ox-carts
Yvonne 8A	2 ox-carts	1 ox-carts
<p>The above table is a comparison of 2005/06 and 2006/07 maize harvest for affected households. The table reveals that, apart from one household, there was a drop in maize harvested during the time that the households had a patient. Mukupa's household's production was stagnant.</p>		

Table 9: Comparative household harvest for 2005/6 and 2006/7

Non-affected household	2005/2006 harvest	2006/2007 harvest
Michelo 1B	1 ox-cart	3 ox-carts
Hachimba 2B	60 ox-carts	80 ox-carts
Mukuni 4B	1 ox-cart	1 ox-cart
Banji 5B	Eight 50kg bags	During this farming season he worked on his father-in-law's farm
Mweete 6B	5 ox-carts	5 ox-carts
Hakalima 7B	2 ox-carts	3 ox-carts
Kachimba 8B	1 ox-cart	2 ½ ox-carts
<p>The above table is a comparison of 2005/06 and 2006/07 maize harvest for non-affected households. Apart from two households that were stagnant, the rest of the households recorded an increase.</p>		

TB caused the households to become more food insecure because they were living in fear of where they would get their next meal. A family is only food secure when their food system operates in such a way as to remove the fear that there will not be enough to eat (Maxwell 1988). Scudder observed in his study among the Tonga that disease, among many other factors (irregular rainfall, animal and plant pests), caused variation in crop yields between households. "Each time a gardener is stricken and confined to his hut, valuable time is taken away from essential agricultural activities," (1962:240) - this leads to food insecurity. Similarly, a survey conducted by the Zimbabwe Farmers' Union revealed that agricultural output declined by nearly 50% in the households affected by AIDS (Kwaramba 1998).

Although only focusing on HIV, many studies (Barnett and Blaikie 1992; Donovan et al. 2003; Donovan and Bailey 2006; Drinkwater 1993; Gillespie 1989; Gillespie and Kadiyala 2005) show the social and economic consequences of the loss of labour power caused by illness. In addition, these studies prove that chronic illness has the power to destroy not

only family life but also agricultural patterns which lead to reduced production and food insecurity.

To gain further insight into my informants' nutritional status, apart from recording maize production, I carried out anthropometric measurements in children under the age of five in both the affected and non-affected households. The measurements were done at the beginning and at the end of fieldwork – namely October/November 2006 and May/June/July 2007. In the affected households, 13 children's measurements were analysed and in non-affected households, 11 children's measurements were analysed.

The findings³⁷ show that both affected household and non-affected households had a poorer nutritional status at the time of the second measurement (May/June/July 2007). On average, affected households exhibited greater losses of weight and arm circumference³⁸ at the second measurement than non-affected households; and some affected households exhibited large degrees of weight loss. Arm circumference is a measure of fat stores, and reduction in fat stores indicates loss of nutritional status in the immediate term. Therefore, both affected and non-affected household experience seasonal losses in nutritional status between October/November and May/June/July the following year³⁹, but on average, affected households are in far greater nutritional jeopardy at the end than non-affected households. Although the numbers are small, this still suggests the negative impact of TB on the nutritional status of a household.

³⁷ I wish to acknowledge the assistance of Deborah Crooks in analysing this data on anthropometric measurements. Deborah Crooks is a nutritional anthropologist from the University of Kentucky who has worked extensively in Southern Province (see for example Crooks and Cliggett 2004; Crooks, Cliggett and Cole 2007) She trained both myself and my research assistant in the theory and practice of anthropometric measurements in September 2006.

³⁸ This measurement is referred to as the upper arm circumference z-score or MUACZ.

³⁹ We would surmise that although the 2006/7 farming season was better than the previous year, the harvest and effects of this improved season had not yet kicked in nutritionally for all the households – their worsened nutritional status in May/June/July 2007 was therefore a reflection of the previous 2005/6 season.

Many studies on food security in households affected by either HIV or TB do not compare affected households and non-affected households. However, supportive literature on TB and food security or HIV and food security shows that households are more likely to face food insecurity because of chronic illness (FASAZ 2003; FFSSA 2004; Kamolratanakul et al. 1999; Killewo 2002; WFP 2004b; ZARI 2006; ZVAC 2005).

4.2.3 Food consumption patterns within the household

Having looked at the food security of the household as a whole I would like to now focus on the food security of the individuals. Hoddinott (1999:10) in his guide to choosing outcome indicators of household food security states, “Observations made in many parts of the developing world suggest that as households become better-off, they consume a wider variety of foods.” A single visit by an observer to both the TB household and the non-TB household would be deceiving in the sense that it would suggest that affected households are doing relatively well economically due to the variety of meals cooked in a day, while non-affected household’s meals are solely composed of vegetables and *insima*. (See Table 10 and 11 for an example of non-affected versus affected household’s meals in seven days.)

The reality of the matter is that a normal diet for the rural families of Pemba/Batoka is usually vegetables with *insima* (see Colson (1958b) on Plateau Tonga diet). On some days, vegetables can be replaced with *kapenta*, soya pieces or milk. It was observed that affected households had a great variety of foods cooked in one week as compared to non-affected households because meals eaten by the patient were usually different from meals eaten by the rest of the household. Patients were served eggs, chickens or meat, while the rest of the household ate vegetables with *insima*.

Table 10: Beatrice's household meals eaten in seven days

This first column shows meals eaten at breakfast and supper	These four columns show meals eaten at lunch and the source of each meal			
Day	Main dish	Ingredients and source of main dish	Relish	Source of relish
Saturday No breakfast. Wild okra from the bush with <i>insima</i> for supper.	<i>Insima</i>	Bought maize then took it for grinding	Rape	Market
Sunday Porridge for breakfast. <i>Bondwe</i> (vegetable) from the bush with groundnuts, chicken and <i>insima</i> for supper.	<i>Insima</i>	Bought maize then took it for grinding	Chicken	Present from Enesia's parents
Monday Buns and tea for breakfast. Dry fish (market) and <i>insima</i> for supper.	<i>Insima</i>	Bought maize then took it for grinding	Soya pieces	Market
Tuesday Porridge with milk for breakfast. Dry meat (Gift) and <i>insima</i> for supper.	Pumpkins			From Mubanga's father
Wednesday Porridge for breakfast. Soya pieces, <i>rape</i> (market) and <i>insima</i> for supper.	<i>Insima</i>	Bought maize then took it for grinding	Sour milk	Market
Thursday No breakfast. Eggs, <i>Rape</i> (market) and <i>insima</i> for supper	Pumpkins			From Mubanga's father
Friday Porridge for breakfast. Cabbage, meat (market) and <i>insima</i> for supper.	<i>Insima</i>	Bought maize then took it for grinding	Cabbage	Market
This Table shows meals that were eaten by Beatrice's household in seven days in February 2007. Unlike the comparative household, most of their meals were either gifts or bought from the market. Unlike the comparative household that had vegetables throughout the week, Beatrice's household had some chicken, milk, dry meat, soya pieces, eggs and fish. Some times the family did not have breakfast.				

Table 11: Comparative household to Beatrice - meals eaten in seven days

This first column shows meals eaten at breakfast and supper	These four columns shows meals eaten at lunch and the source of each meal			
Day	Main dish	ingredients and Source of main dish	Relish	Source of relish
Wednesday Nothing for breakfast. <i>Insima</i> with Okra for supper.	Nil			
Thursday No breakfast. <i>Insima</i> with pumpkin leaves for supper	<i>Insima</i>	Bought maize and took it for grinding	Pumpkin leaves	Garden
Friday No breakfast. <i>Insima</i> with pumpkin leaves for breakfast	Nil			
Saturday No breakfast. <i>Insima</i> with cabbage for supper	Nil			
Sunday No breakfast. <i>Insima</i> with pumpkin leaves for supper	<i>Insima</i>	Bought maize and took it for grinding	Cabbage	Pemba market
Monday No breakfast. <i>Insima</i> with Black jack leaves for supper	<i>Insima</i>	Bought maize and took it for grinding	Pumpkin leaves	Garden
Tuesday No breakfast. <i>Insima</i> with Cabbage for supper.	Nil			
Wednesday No breakfast. <i>Insima</i> with pumpkin leaves for supper	<i>Insima</i>	Bought maize and took it for grinding	Pumpkin leaves	Garden
Thursday No breakfast. <i>Insima</i> with cabbage for supper	<i>Insima</i>	Bought maize and took it for grinding	Pumpkin leaves	Garden
Friday No breakfast. <i>Insima</i> with Black jack leaves for supper	<i>Insima</i>	Bought maize and took it for grinding	Pumpkin leaves	Garden
This table shows meals eaten in seven days by the comparative household to Beatrice's household in February 2007. The source of most of their meals was their own garden. Their meals were composed of vegetables throughout the week. The people mainly ate one major meal – lunch. Some times they could eat breakfast and lunch and other times they would not.				

The above discrepancy was mainly because the patients demanded special foods high in protein and carbohydrates - for example fish, chicken, eggs, fruits, soft drinks, meat, sausage - and refused to eat vegetables. Some of the patients complained openly and made sure their demands were met, or had a belief that - because they were patients - they were entitled to the special food. On several occasions, I asked some of the nine people how other family members reacted whenever they asked for special foods. The answers I got from the patient revealed that they felt they had a right to special food. Rocky once said, *"They know I am sick so they understand."* Mukupa's demand for special foods was a way of getting attention. *"I am fine so I eat a lot. However, my grandmother does not know that I am fine. I want to stay sick so that they can care for me throughout. I like the way every one pays attention to me."* For others, special foods were a boost or a motivation to eat, especially during the time when they had lost appetite. Nevertheless, whatever the reasons for the demands, the caregivers usually went out of their way to ensure that the patient was comfortable.

"I tell you it is a problem. Their food desires changed all the time. Today they want this the other day they want that. I do not know how I managed. Sometimes one would have the appetite and then the other would not. On other days, they both wanted to eat too much. There were days when Molly wanted eggs and Innocent wanted fish or chicken. It meant me cooking eggs, then fish for Innocent. Innocent was worse because he refused to eat roller meal, he wanted insima made from breakfast meal. Then also I had to cook for the rest of the family," Rachael, mother to Molly and Innocent, recalled a month after her children were cured of TB.

Because the caregivers were trying to meet patients' demands and believed better food would help, the patient was given more attention and care. An inappropriate allocation of food within the household may exacerbate the effect of an inadequate household food supply on certain household members (Lipton 1983; Senauer et al.1988). The sick person ate more at the expense of other household members because there was more protein and fruit in particular in their diet. When food was prepared, the patient was always served first. In some cases, the rest of the household was served *insima* and vegetables throughout

the week while the patient was given either eggs or meat. In half of the households, when a chicken was killed, it was usually for the patient. The caregiver would cook a small portion for the patient and the rest would be roasted or smoked on wood to preserve it for a week or so until the patient finished the whole chicken.

I could see that the above affected other members of the household, for example, the children in Molly's household started pretending to be patients so that they could have nicer food. *"The twins wanted some of my chicken but I did not want to share so I give them the legs and the neck. When they saw that I had been allowed to eat the chicken without sharing the next day they were pretending to be sick so that they too can have a chicken to themselves,"* narrated Molly. Greenblott and Greenaway (2006) show evidence that children and orphans have increased susceptibility to food insecurity when they live in households with at least one sick adult.

Other household members showed that they too would have loved to eat nicer food. On days when I sat to chat with some household members I would ask them to share with me what they thought was a nutritious meal. Usually the answers were similar to the special foods that patients were given - sausage, chicken, rice, and soft drinks. From the discussions, one could tell that other household members desired similar foods to the patient. Whereas in the non-affected households all members received the same type of meal, with an age-biased distribution which favoured the household adults (Abdullah and Wheeler 1985; Chaudury 1983; Hassan and Ahmad 1984), in the affected household, there was both an age- and illness-biased distribution. That is, not only did the adults get more food than the children, but also the patient was given a different meal from the rest of the household members. Although the patients were usually served a different meal from the rest of the household members, the food was never sufficient because they always complained about not having enough.

4.2.4 Hunger and TB medication

One day when I had gone to visit Beatrice I found her seated outside listening to the radio.

Three of the children, Mwaka, Cheelo and Patrick, were playing outside. Beatrice informed me her husband was doing some piecework in the neighbourhood, her stepson Tom had gone to herd his grandfather's cattle and Enesia (Beatrice's co-wife) had gone to look for food. A few minutes later Enesia came back with four mangos and two sweets. When Beatrice saw the mangos, she immediately asked for one. Enesia answered by saying, *"I only brought four mangoes for my four children, they have been crying because they are hungry. You are much better so you do not deserve a mango."* Beatrice continued asking for the mango as if she did not hear what Enesia said. After exchanging a few more words, Enesia finally gave Beatrice the mango. In no time, Beatrice had finished eating her mango and she started asking Enesia why she had brought so few mangos. Enesia had begged for mangos at her friend's house that lived three compounds away.

Enesia turned to me and explained, *"She eats more than the children. You saw how she ate that mango. She eats so fast and wants food all the time. Apart from our usual normal meals, we collect fresh caterpillars for her and prepare them at whatever time she requests for food. She likes meat but I told her that our chickens are finished. She wants us to kill a chicken every other day!"*

Beatrice was not the only one in such a situation, all the participants complained of hunger due to their TB medication. During the course of illness, their appetite fluctuated from low to high. The appetite fluctuation came with desires for different kinds of foods. The common demands were fish, food cooked with oil, meat and soft drinks. I recall Yvonne saying, *"The difference is that before TB whenever I felt hungry I would still go without eating anything - that is if I have no food - but the TB hunger is worse. When you feel hungry, you need to eat, you just have to find food otherwise your body shakes and you feel generally weak. TB hunger can cause you to steal!"* I asked Yvonne's daughter to explain how her mother's food desires had changed during the period that she had been looking after her. In response she said, *"Before TB my mother used to eat whatever was prepared but now she chooses certain foods. She likes asking for special foods. She demands for fish, eggs, chicken, sugar, but we cannot afford these foods."*

Alex was also having a problem with containing his hunger. *"Now that I am taking the TB drugs, I feel very hungry and I have never had such hunger. Before I started the drugs, I used to eat in the morning and sometimes at 10:00 hours I would have a drink but from the time I started the medicine I eat all the time."* His family was amazed that Alex could not move or bath himself yet he was able to eat so much! Within a month of living with his mother and brother, the family complained Alex had "eaten so much food". His mother once said, *"Alex is not able to walk or bath himself but eats too much and he is too demanding."* Alex refused to eat whenever he was offered anything he did not feel like. Despite this resentment, the family was anxious about his illness and wished desperately for him to recover, and they provided what they could.

Table 12 shows Alex's household expenditure for the month of October 2006. Alex's mother, Anita, informed me that this was the biggest expenditure she and her family had ever made. She complained that, since Alex joined them, they had spent too much money on his needs. In addition to the list below, George - Alex's brother - slaughtered one of his goats worth K45 000 for the patient. Though other members of the family had taken part in eating the goat, George was unhappy about it because he would not have slaughtered if Alex had not requested to eat goat. During the same month, George also slaughtered about six of his chickens for Alex.

Maxwell and Frankenberger (1992:8) summarised food security as "secure access at all times to sufficient food for a healthy life". The above complaints of hunger by patients simply show that they did not have a secure access to food to fulfil their hunger. Similarly the complaints by the caregivers show that there was not enough food in the home to meet the demand of the patients. Thus the demands for special foods by the patients were causing a strain on households that were already food insecure.

Table 12: Alex's household expenditure list for October 2006

Cash or kind	Expenditure	Where was the money spent (or to whom)	Total bought	Price/unit in K	Total value in k
Cash	Bathing soap	Kasiya	2	2800	5600
Cash	Washing paste	Kasiya	2	1800	3600
Cash	Salt	Kasiya	4	500	2000
Cash	Sugar	Kasiya	4	500	2000
Cash	Juice	Pemba	2	7000	14000
Cash	Rice	Pemba	5	3500	17500
Cash / credit	Bread	Kasiya	30 - one on each day	2800	84000
Cash / credit	Milk	Kasiya	30 - a pint every day	2800	84000
Cash	Sausage	Pemba	1 pack	5000	5000
Cash	Sugar	Pemba	5 small packets	3800	17500
				Total	K 235200

In the above discussion, we have looked at the impact of illness on food. We have established that TB can cause poor households to become more food insecure because it disturbs farming patterns and other members of the household can be neglected at the expense of the patient. The next section will reveal that households were not only having problems with food but also with medical costs.

4.3 I am suffering! A cry of the poor due to too many costs

“I am suffering!” lamented Leo’s mother who had been caring for him for more than five months. “Before Leo got sick,” she went on to explain, “I used to have enough food, but this year has been full of hunger. From the time I started trying to find out what was wrong with my son I have been using money to take him to the hospital and to get food for him but it has been a problem to find money. So far I have used more than K140 000. I also sold some chickens to help me care for my son with the hope that he will get better but there is no sign of improvement. Where will I get the money, because now, I have nothing? I am really suffering!”

“I am suffering!” - I had heard this phrase many times during my fieldwork from both the caregivers and the patients. Indeed TB was causing suffering. Firstly, the patients spent a lot of money during the treatment-seeking period - all reported to have spent not less than K200 000 during that time moving from one health centre to the other. In addition, some like Leo’s and Rocky’s mother had visited traditional healers where they paid more than K20 000. Thirdly, apart from Mukupa, all the patients had been admitted at least once (twice in the case of Alex and Beatrice) at either a clinic or hospital for not less than two weeks. All patients reported to have spent not less than K150 000 on foods for the patient and transport to the hospital. Transport costs were especially high for the caregivers who had to move between home and the hospital.

Table 13: HIV status for the nine participants

The table shows the HIV status of TB patients	
Patient's name	Status
Rocky	Positive
Alex	Positive
Molly	Positive
Innocent	Positive
Leo	Positive
Beatrice	Positive
Mukupu	Positive
Victor	Negative
Yvonne	Negative

For those also living with HIV, there were additional costs. As can be seen in Table 13, seven out of the nine people suffering from TB were also living with HIV – six of them found out their HIV status while sick with TB (Alex knew his status before having TB). These co-infected patients had additional transport costs incurred by having to go to the hospital to access ARVs.

4.3.1 Accessing ARVs

Access to antiretroviral therapy (ART) in Zambia was limited and available only through private medical practices to the country's affluent population until 2004 (Stringer et al. 2006:782). According to the Treatment Advocacy Literacy Campaign - TALC (2005), on 13 June, 2005, the Zambian government announced that ARV drugs would be made available free of charge through all public health institutions in the country. In its message government said it had a "moral obligation" to abolish all cost barriers to accessing ARVs "because of the overwhelming poverty levels.... and high cost for accessing ART" (TALC 2005).

Unfortunately the reality is that many rural Zambians still cannot afford the treatment they need because costs are still very high and access is a long, difficult process (ibid 2005; Jones 2005). Policies to provide free care do not do away with other substantial costs, such as travel, food expenses and unofficial medical charges as observed in Afghanistan by Schütte (2006), in Bangladesh by Nahar and Costello (1998) and Khan (2005), in China by Lee (2001) and in Tanzania by Abel-Smith and Rawal (1992).

People in Pemba/Batoka refer to the ARVs as *musamu wabakuwa* meaning medicine for whites. It does not literally mean a white skin but white as a metaphor for rich. For instance a man from the village would greet his friend from town by saying “*Kamwaba makuwa!*” meaning, “How are you rich person!” Therefore referring to ARVs as *musamu wabakuwa* simply means it is medicine that only rich people can access. As Mogensen (2005:1) states, “In Uganda drugs are available but largely inaccessible, and in the space between availability and inaccessibility there is room for dilemmas that cause not only economic but also social disruption.”

Indeed accessing ARVs for the seven people living with HIV created new dilemmas and new uncertainties in their lives. In the first place, it is important to remember that these were people who had been very sick and ailing for some time, which had thus dented both their self respect and household income. The patients had to rely on household members’ income and household assets for subsistence and medical care, as they were no longer able to work themselves.

Living in a rural area was a big disadvantage for these seven co-infected patients because they all lived far from the two public hospitals where they could access ARVs. Choma Hospital is 60km away from Pemba and Monze Hospital is 40km from Pemba. Motorised transportation was the quicker way to get to the hospitals but costs were prohibitive for majority of them. It costs between K6 000 and K10 000 to get to Monze depending on one’s negotiation skills with the bus conductor; and to get to Choma one would spend between K10 000 and K15 000. The cost to the hospital was often doubled if the patients were very sick and needed the caregiver to accompany them for support and assistance

with tasks such as walking and going to the toilet. As noted by Foster (1993:6) in a study done in Monze District in Southern province, “55% of patients are accompanied by a relative or friend at the hospital (the helper). These people provide social and psychological support.”

Apart from the distance and associated costs, accessing ARVs was not easy because of the process involved. Molly was the first of the seven to start ARVs and she used to tell me stories about the days she spent at the clinic. *“The ARV clinic is a long process. You go early in the morning and get back late at night.”*

Molly started trying to access ARVs in October 2006 when she was admitted to Choma Hospital for TB, and she was finally enrolled in the last week of January 2007. The process took long because sometimes she was given an appointment for another day. On other days she never managed to see any clinic staff because of the long queues.

“Hey! It is not easy at all. It is not even easy to open a file. First, there are many papers to fill in and many questions to answer. In addition, there are so many people waiting for the same service so there are so many queues. But once a file is opened for you then things become a lot easier,” Molly would say.

When she finally started taking ARVs I asked her how much she had spent. *“About a K100 000 or more. I used to encourage my parents to look for money so that we could go to the hospital. Other people that I used to find at the ARV clinic have not yet managed to get the drugs.”*

Innocent too complained about the long process. *“There were many problems. When I first went to the ARV clinic, I was told to give blood so that tests would be done. When I went back for my results, I was told that the results were lost. Before I left I gave them more blood. When I went back the second time I was told that my blood was destroyed because there was a power failure so my results were not ready. I gave blood the third time and it finally went well. I was not given the medicine the same day I had to go back. On my fourth*

trip, I was given aspirins for two weeks and an appointment was made for me to visit the clinic after two weeks. I went and then some tests were done. I made about five trips to the clinic before I finally started my ARV drugs,” Innocent recalled.

Each trip to the ARV clinic cost K20 000 so, by the time he had done five trips, Innocent had spent over K100 000. In this particular household, this was a double expenditure for Innocent’s parents because Molly, too, had visited the clinic many times before she could start taking ARVs.

“We have spent about K200 000 on transport to Choma Hospital for both patients. They had to go for review and Molly had to start her ARV treatment. ARV treatment takes a long time so she had to keep going back to the hospital and that is why we spent so much money. Money is not easy to come by. We borrowed some of that money from our friends and from my daughter Gertrude. The most pressing is transport money to the hospital. Last year my daughter-in-law passed away because we did not take her to the hospital in good time. I do not want that to happen to my two children. People die because they have no money to go to the hospital. Others also default due to lack of transport money to the hospital so my husband and I are doing the best we can so that the patients can manage to go for their reviews,” Molly’s mother narrated

It was difficult to find money, but some caregivers, like Molly’s parents, were determined that their children start ARVs no matter what it would take, and that is why they borrowed money. I was interested in what was happening at the ARV clinic and Molly’s stories made me more curious. My research assistant and I decided to spend a day at the clinic.

4.3.2 A day at the ARV clinic

Choma Hospital, 20 March 2007

Florence and I arrived at Choma Hospital around 09:00. We went to the office of the sister in charge and introduced ourselves. She was very welcoming and told us to go ahead with

our programme.

We walked to the ARV block. It is a tiny building made of concrete blocks and iron roofing sheets. The clinic is so small that not all the people we found there could fit inside. Efforts are being made to extend the building - another room, which has been built to roof level, is attached to the ART clinic. As we approached the clinic, I saw over a hundred people of different age groups, but the majority looked to be between 25 and 55 years, and mostly majority women.

Generally, the people at the clinic are of low social status. One could see from the type of clothes and shoes they wore: Most of them were looking shabby; some had shoes while others were walking bare-footed. They looked tired and hungry. A few were sleeping on concrete as they waited to be attended to. There were two benches but because there were too many patients, these were not enough. The patients picked up bricks from the unfinished building and use them as seats. We sat on the bricks while we waited, and they were uncomfortable.

The staff⁴⁰ is very friendly and hard-working. The following is what we established about the process of accessing ARVs:

First step

A patient goes to the ARV clinic with their HIV positive results. The patient is given an appointment to go back to the clinic after two weeks.

Second step

A file is opened for the patient. The doctor who does the physical check-up sees the patient and the patient's history is established. A liver function test is also done. The patient is given some septrin⁴¹ (co-trimoxazole) to boost the immunity, and some multivitamins. In

⁴⁰ We found seven people working there - one nurse, two clinical officers, and four helpers. They work long hours - throughout lunch and usually clocking off after 18:00 - in order to attend to most of the patients.

⁴¹ Septrin infusion tablets, forte tablets and suspensions all contain the active ingredients sulfamethoxazole

some cases the patient's CD 4 count is assessed at this stage. The patient is given an appointment to go back to the clinic after two weeks.

Third step

After two weeks the patient is supposed to go to the clinic with a "buddy"⁴². When the CD 4 results are ready, the doctor can then decide whether to give the patient ARVs or not. The patient is given an appointment to come back after two weeks on treatment.

Fourth step

An assessment of patient's adherence to ARVs is done, after the patient has taken the drugs for two weeks. The staff assess the side effects, and whether there is need for a change of drugs or not.

It should be noted that all the visits and tests done at the clinic are free. The costs that patients incur are due to the fares to and from the clinic. In some cases some patients do not manage to go past the first step in one day due to the amount of queuing involved. Therefore patients end up with four to five trips to the clinic before they can start the ARV drugs. This implies that they have to spend more on transport. We also learnt that in some cases patient are given fewer pills than what is written on the container. For instance, a patient is supposed to have 30 pills in a container but when they go home they find that the container has fewer pills than what is written in on it, in some instances 25 or 26. This means the patient will have to make another trip.

In addition to the above-mentioned trips, the patient has to make a trip to the ARV clinic 10 days before the pills finish so that they do not run out of pills. People who live in our study area (Pemba/Batoka) spend between K10 000 and K30 000 on a single trip. These are poor households who struggle for everything they have; even a thousand kwacha to

and trimethoprim, which together are known as co-trimoxazole. Sulfamethoxazole and trimethoprim are both antibiotics that are used to treat infections caused by bacteria.

⁴² A friend or relative that will remind the patient to drink the medicine every day and also collect medicine on behalf of the patient when she/he is too sick to do so.

buy vegetables is hard to come by. The nurse at the clinic actually mentioned that some of the clients default because they are too poor and cannot afford to pay for transport to the clinic.

While at the clinic we administered a simple questionnaire to 49 patients; 24 women, 21 men and 4 children. Out of the 49 patients, 17 came from within Choma while 32 came from outside Choma⁴³. We learnt that out of the 49, 13 patients got to the clinic by foot, 7 cycled to the clinic while 29 had travelled by bus. When we asked the respondents how long it took them to get to the clinic; we learnt that only nine people took less than an hour to get to the clinic, the rest took over two hours to get there.

The patients complained about the staff taking a long time to attend to them. During the observation some patients were shouting at the staff for taking too long. They accused the staff of being lazy and not concerned about their welfare or how long they stayed in the queue. What surprised me the most was the nature of the staff, who did lose their cool but later explained that patients usually have high tempers, and each one thinks they are sicker than the others. Because of that, each patient wants to be attended to first, but that is impossible.

One of the patients shouted from the corridor, "*Citola ciindi cilamfwu buti kubona naa kulananya mulwai omwe? Sena mwaanda wa mawoola?*" (How long does it take to attend to one client? Hundred hours?)⁴⁴ Another shouted, "*Muntu uuli anzala, muntu ukalede! Ndimvwide nzala kapati mpoona mutola ciindi cilamfwu kundilanganya, sena muyanda kundinyemya?*" (A hungry man is an angry man! I am so hungry and you are taking so long to attend to me, do you want me to get angry?)

We observed that the main reason why each patient takes a long time in the screening

⁴³ Some patients came from Kalomo, Pemba, Batoka, Muzoka, Demu and villages surrounding Choma

⁴⁴ The question implied that the nurse and clinical officers were taking too long to attend to one patient.

room is because the nurse has to administer a questionnaire that helps to determine if the drug is reactive or not, the side effects⁴⁵ of the drug, and any other problems that the patient is facing. For those who are given the drug for the first time, the nurse explains in full how the drug should be taken, they also emphasize that it should not be shared⁴⁶. The nurse also explains to the patient that he or she should be free to visit the clinic any time they feel unwell and should not only wait for the date of appointment.

From the questionnaire, we learnt that people take a long time at the clinic. Out of the 49 respondents, 16 people said it was the first time for them to visit while the rest (33) had visited the clinic before. Table 14 shows that the last time the 33 people visited the clinic, no one spent less than an hour, two people spent 1 to 2 hours and another two spent 2 to 3 hours while 29 people spent more than 3 hours before they could go home. The nurses said the delay in attending to patients was due to shortage of staff at the clinic.

Table 14: Time spent at the clinic

Time spent at the clinic	No of respondents
Less than an hour	0
1 to 2 hours	2
2 to 3 hours	2
More than three hours	29

⁴⁵ Side effects include nausea, vomiting, diarrhoea, persistent headache, rash, severe leg pain, fever, difficulty breathing, swelling, fatigue, severe abdominal pain and dizziness/light-headedness.

⁴⁶ We were told a story of how one woman shared the ARVs with her brother when he fell ill. The brother reacted to the drug and got sicker. That is when the woman rushed to the ARV clinic with her brother. She asked the staff how come the drug was able to work for her but not for her brother.

In terms of transport costs, the questionnaire administered showed that more than half of the respondents had used at least a K5000 to get to the health centre (See Table 15). For rural people living on less than a dollar a day this would be very expensive.

Table 15: Amount of money used to get to the health centre

Amount used to get to the hospital	No of respondents
Nothing	12
Less than K5000	1
Between K5000 and K10 000	2
Between K10 000 and K30 000	24
More than K30 000	10

Talks with the patients revealed that most of them did not have a proper meal before going to the clinic. When asked what they had for breakfast, some of them said they had *ceelee* (porridge, if it is little porridge they say *keele*), others said they had *chibwantu* (sweet beer), some also said they had *insima*. Only two people said they had *cinkwa* and *tii* (bread and tea) and majority of the patients said they had no meal at all. We decided to ask this question to the patients after many of them became angry that the staff were enjoying refreshments.

From the time we started the observation (09:40 up to about 14:40), we did not have anything to eat or drink. My research assistant and I thought it would be a good idea to have a drink. We then bought 10 drinks, eight for the staff and two for ourselves (one of the staff went out to buy the drinks). As soon as she came back and distributed the drinks some of the patients started complaining. *Twasiika awoola lya sikisi koloko kwiina a ncotwalya. Pele nywebo mujisi bubi kulitesya a moyo!*" (We came around 06:00 and have

not eaten anything but you are busy having drinks!) One woman also shouted, “Am very hungry, give me that drink.” “*Ndendi mulwazi kutali ndinywe. Ndime ndeelede kunywa tutontola kutali ndinywe!*” (I am the patient and not you. I deserve the drink more than you!) Others answered in response, “*Inzya amulete tutontola tunywe!*” (Yes bring the drink, we have it!)

The nurse then went on to explain that the patients need food supplements because most of them are very poor. She wished that the government or an NGO could provide food supplements for the patients. She told us that on rare occasions they have lunch and some patients do not complain, but other times they complain.

Before we could end our observation, we asked the staff to share with us some of the challenges they face. They informed us that, apart from limited staff at the institution and lack of food supplements for the patients, they also lack transport, as they would like to follow up patients who default because of lack of money.

As can be seen from the above observation, food is a serious issue with regards to those people taking ARVs. Many of them want food⁴⁷. The observation also revealed that distance to the health centre, the costs, and the process were the main factors for delaying patients’ access to ARVs on time. Because of the latter, only four out of the seven TB/HIV patients managed to start ARVs. Alex died before he could start taking the ARVs. As can be seen from his case study, when he was told to go to the ARV clinic by the nurse, he did not have the transport money. By the time he found the money it was too late, he had TB, and had to start the process of curing TB.

⁴⁷ Data collected on food in relation to ARVs was limited. There is need to pursue further investigation on whether TB patients who are on ARVs continue to demand special foods a year or more into treatment.

4.3.3 ARVs for the seven people who were co-infected

Rocky had only visited the ARV clinic once but could not find money for further visits, Leo managed to start ARVs having sold all his best clothes and after his mother had borrowed money from her friends, but the flow of cash was not stable thus on two occasions Leo was forced to miss his review days. *“Transport to the hospital has been a problem. It is difficult to find money to take me to Monze. I cannot count all the times that I have been to Monze and each time I make a trip I have to sell one of my belongings. I wonder if I will have clothes left after this illness,”* Leo complained. I wondered what would happen to Leo since he was missing appointments and when I asked the nurse, she said, *“If the drug routine is broken, even for a few weeks, the HIV virus will increase and will develop resistance to the ARVs.”*

Table 16: ARV condition for the seven co-infected participants

The table shows the name of patient on ARVs and when the patient first accessed ARVs	
Patient's name	ARV condition
Rocky	Not yet
Alex	Died before he would start
Molly	26 January 2007
Innocent	14 th March 2007
Leo	29 January 2007
Beatrice	18 April 2007, died in May
Mukupa	Not yet

Beatrice was willing to start ARV treatment but she found it hard to find money for transport to Monze hospital, especially since her husband and her co-wife were not supportive. Her husband refused to give her transport money to the hospital. *“He does not want to give me money to go to Monze Hospital to collect ARVs. The other day I asked him*

for transport money to Monze, he refused,” complained Beatrice. “Why did he refuse?” I asked. “My husband does not want me to start taking ARV drugs,” she replied. It took a long time for Beatrice to start taking ARVs and by the time she started them, she was very weak and depressed. Beatrice died within a month of starting ARVs.

Fortunately, before I ended my fieldwork in Pemba/Batoka, an ARV clinic was established at Pemba Clinic in June 2007. Many people around the community were happy with the news. I remember Molly’s excitement when I shared the news with her, *“No, I do not know, that is a wonderful thing! I think I will change from Choma to Pemba. It is nearer to home. Why can’t you bring the ARVs for me? That way I won’t have to look for transport money to Pemba!”*

Indeed, it was a wonderful thing, but people still face problems in accessing ARVs because, for some, distance remains a barrier, Molly still has 20km to travel and Rocky has 32km to travel to reach Pemba. In addition to this, the clinic is short-staffed. Therefore, some people are sent back and given different appointment dates. As mentioned by Nicholas et al (1991:6) in their clinical AIDS research that evaluates cost effectiveness in the developing world that it is of no real benefit to tell people with AIDS in a poor, developing society: there is a drug for their condition, but it is out of their reach because of resource constraints.

4.4 Struggles for agency in the face of TB and AIDS

From the early 1980s, AIDS research by anthropologists has grown rich and diverse (Schoepf 2001). The biology and cultural context of the disease has been studied in detail, and its spread across the globe is well documented (Bolton and Singer 1992; Glick-Schiller 1992; Mogensen 2005; Schoepf 1998; Singer 1998; Treichler 1999). “These richly contextualized studies allow the voices of sufferers and people at risk to be heard, by incorporating narratives, texts of interviews, observations, and public speech.” (Schoepf 2001: 337). However, anthropological inquiry needs to move beyond the construction of the pandemic itself, to examine how households survive when they are faced with not only HIV but both HIV and TB (Farmer 1999) because a third of the 40 million people living with HIV today are also co-infected with TB (Allafrica.com 2006; WFP 2004a)

In Pemba/Batoka, households that were affected by HIV and TB borrowed extensively and sold off some of their assets to enable them meet all the costs. Literature that has looked at how rural households survive when affected by HIV/AIDS (Barnett and Blaikie 1992; Baylies 2002; Gillespie 1989; Kwaramba 1998; Waller 1997) refers to such actions of borrowing and selling of assets as coping strategies. Much of the coping strategy literature (Corbett 1988; De Waal 1989; Devereux 1993; Watts 1983) arose in response to the famines in Africa and, as a result, has particular concerns. Its primary concern is whether it is possible to intervene in a way that supports local strategies, rather than undermining them (Goudge and Govender 2000; Rugalema 2000). (For example does providing food aid prevent the poor from having to sell for the purpose of consumption?).

Davies (1993) and Rugalema (2000), however, question the usefulness of the “coping strategy” approach in analysis of household responses to illness. They state that coping strategies, by definition, are about success rather than failure - “to say that households are coping implies they are managing well” (Rugalema 2000). Their main argument is that employing the “coping strategy” framework is unrealistic and insufficient to explain the effects of the epidemic on rural households. From the experiences of people affected by HIV and TB in Pemba/Batoka, I concur with Rugalema and Davies. The use of coping

strategies “obscures the real experience and suffering of individuals and households,” (Rugalema 2000). Selling of assets and borrowing means individuals and households have failed to cope; in fact such actions lead to further impoverishment.

Although Rugalema and Davies do not offer an alternative name to such actions, I will refer to them as “struggles” - to move about strenuously so as to escape from something confining. In this case the households tried to escape the pressures of the illness, such as costs and lack of food. Thus in their efforts to escape, the following is what they employed:

Apart from Mukupa, Victor and Yvonne’s households, the rest of the households sold off assets and livestock. *“I sold some of my clothes in exchange for maize. We sold three goats for K70 000, K45 000 and K45000. We used this money to buy food and some was used to buy soap, school requirements for the school children. We also paid for transport for the patients,”* narrated Molly and Innocent’s mother. Leo’s family sold all its livestock; by the time I came to know the family they were left with one chicken and two pigeons and during the course of the study, the chicken and the pigeons were sold off. After that they started selling their special clothes. *“Leo sold his pair of shoes and a trouser. I sold the chicken at K10 000 and I also sold some of my clothes for K40 000,”* Leo’s mother replied when I asked her about her chicken.

Selling of assets in times of illness has been reported in some countries. In the Bangladesh slum described by Pryer (1989) people sold off assets during illness. In India, Dogra (1988) also notes that his respondents were unable to meet health care costs without extensive indebtedness, mortgaging land or animals, thereby endangering their economic viability.

Borrowing money to get food or to pay for other needs was another common practice of all the affected households. By the end of the study, all the nine households were in debt. The only difference is that some households were in more debt than others. The money borrowed came from neighbours, friends, church and better-off households in the

community. Borrowing money led them into debt and left them even more food insecure, especially as interest rates were high. For example, Mary's friend used to charge 50% interest. This type of borrowing is locally known as *kaloba*. It was only the church that did not ask for interest.

Apart from borrowing money, some households borrowed food from friends and neighbours. *"When we run out of food I go to my parents in Mwala to ask for food and they give me two buckets of maize or so. Sometimes my parents send word for me to collect food, I tell my son not to go to school on that day so that we can go and collect the food,"* Enesia said.

Rocky's mother, Beatrice's co-wife, and Leo's mother used to ask for food from their relatives whenever they had nothing to eat. For Leo and his mother they even got to the point of begging for food. When this was not working out well they decided to move to a house where they thought life was much better.

"We had no food at all so my mother thought it is would be best for us to go and live with her sister for a few days. We stayed a week with my aunt. The food was a lot and we did not have any problems in terms of food. I had forgotten how good it feels to have everything that you need. I have suffered a lot. It is embarrassing to go and beg for food in someone else's home. I have no option I have to beg because if I do not I might die. I have been reduced to a nothing. I feel useless. I had everything I needed but now I have nothing," Leo narrated in between sobs.

This trend of moving from one home to another in search of food by patients was also noticed in Innocent, Molly and Alex. At one point during the course of the study, Innocent ran away from home to his sister's house in rural Choma, 45 km away. When he came back to his mother's house, I asked him why he had gone away. At first, he did not want to share that he went away because of food issues but later during the course of our visit, he revealed that he thought his sister's place would be much better in terms of food. He later found that the care he received from his parent's home was better and so he decided to

return. Scudder (1962:244-247) shows how, many years ago, the Tonga people explored many avenues in times of food shortages. He explained that in times of food shortages, people journeyed elsewhere to live with more fortunate relatives; women made baskets, which they traded for food; pots and mats were also traded for food; and begging and theft was practiced.

The habit of borrowing money, and selling off assets and livestock, meant that affected households lived hand to mouth. They did not save or invest. The goal for the affected household was to find food and to meet medical costs. As can be seen from Beatrice's household, a child was taken out of school on some days because he had to collect food.

During the course of fieldwork affected and non affected families were given cards to record all monthly expenditures. The cards were checked each week and collected at the end of the month. All items on each card were grouped into food, non food items and medical costs. This was done for all households. After wards the items were analysed and using Microsoft excel I was able to come up with some tables. The findings revealed that non-affected households spent more on farm implements such as spare parts, fertiliser, seed, and school requirements for children; while the affected households usually spent 90% of their money on food and transport to the health centre (See Fig. 17). I further observed that non-affected households spent some money on lotions, paraffin, matches and candles, which were rarely on the expenditure list of affected households.

In some households a pen and paper was given to one member to record what they harvested and then Florence and I double checked the following day since we could not spend time with all households at the same time. It is important to note therefore that all information on harvest was collected by participant observation and through informal and formal discussions with the families during the time spent with them³⁵.

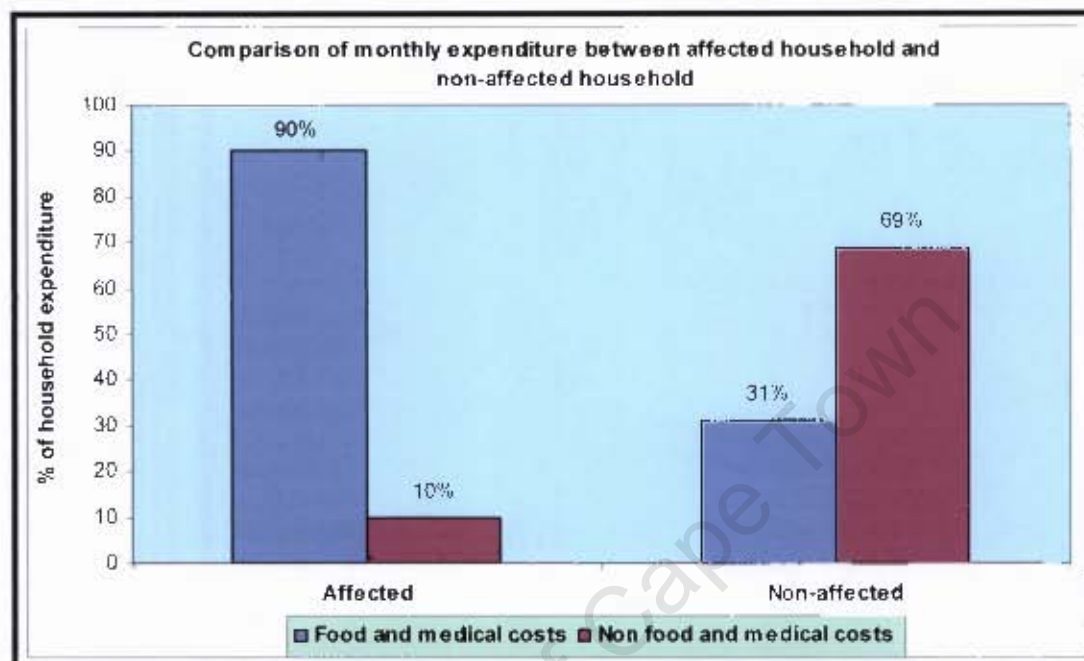
What was observed - as can be seen from Table 8 below - is that the amount of maize harvested in the 2005/2006 farming season was more than the maize harvest in 2006/2007 for seven out of eight affected households³⁶; whereas none of the non-affected households registered a drop in the maize harvested when the two farming seasons were compared (see Table 9).

A drop in maize harvest meant shortage of food sooner than expected. Many of the affected households as compared to non-affected households had no maize in the *butula* during peak months of April, May, June and July. The affected households were also worried about how they were going to survive throughout the year since they did not have sufficient quantities of food which were consistently available, like their counterparts had. When I visited Innocent's family in June 2007, they barely had any maize left in the *butala*. *"We have no food and we fear that we might starve. Because of caring for two patients, we did not put much effort in our field. All our resources were spent on money to the hospital and nice food for the patients. We were scared of losing two children at once. Now that they are fine we are happy but we do not know how we will survive the rest of the year because we hardly have any food,"* complained Molly's father. Yvonne too was worried about how she would feed her family since she was not able to do her normal work, especially since all but two of her six children were disabled. *"Life has changed; it is difficult for me because I am sick and unable to find money to care for my family. I worry about how I will look after my children, how I will feed them and where I will find*

³⁵ Note: this is a tasking method and can only work best when dealing with a very small sample.

³⁶ Note that the author has not attempted to use a standard measurement of maize due to the fact that measurements differ depending on the household. Some households measure their harvest using the metric system (kilograms) while others measure it using an ox-cart.

Figure 19: Comparison of monthly expenditure between affected household and non-affected household



In conclusion, the chapter demonstrates that it is difficult for the poor to manage TB and HIV. Due to illness, the households faced food-related problems. A drop in agricultural production was recorded in six out of eight affected households (2006/7 compared to 2005/6); non-affected households recorded an increase. In addition, TB medication is thought to increase the “hunger” of TB patients and should, it is believed, be taken with food. Therefore the patients put additional demands on households for “special” foods, high in protein and carbohydrates, for example fish, chicken, eggs, fruits, soft drinks, meat, and sausage.

Apart from food-related problems, the households also had to deal with medical costs. Living in a rural area is a disadvantage because of the distance to the health centre and associated costs. Also, accessing ARVs was not easy because of the process involved. Accessing ART in the rural area involved repeated visits to the hospital and substantial costs. An observation at the ART clinic 60kms from Pemba revealed that on average PLWH had to make more than four trips before commencing ART.

Households usually did their best to meet patients' requests, thus some affected households borrowed and sold off their assets. The money raised was spent on food and medical costs. The major consequence was that, while non-affected households spent more on farm implements like seed and fertiliser, the affected households did not invest but lived from hand to mouth.

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CHAPTER FIVE

BURDENED RELATIONSHIPS

5.1 Introduction

People living with HIV and TB are considered “social burdens” because “they are not able to contribute to household income when they are sick” (Bond 2006:185). “Social Burden refers to the impact TB has on individuals as members of households,” (Ogden 1999:856). This implies that the burden of TB and HIV on the patient and the family can be best understood by focusing on the social relationships within the household and within the neighbourhood. This chapter, like the previous one, talks about the impact of TB and HIV but, unlike the previous one, it delves deeper into people’s emotions.

The chapter explores, from the perspectives of my informants, the social networks and relationships that form between patients and their families in the context of limited support, high illness costs, and the psychological impact of TB. In this sense, the chapter outlines a general map of caring relationships, which - by virtue of the “burden” placed on family members - is not always experienced in empathetic terms. “Care” as a social category based on notions of altruism may, in times of stress, be perceived as a burden with stigmatising consequences for the patient.

During fieldwork, six key relationships that revolved around the patients emerged, namely: spouse, parents, siblings, children, neighbours and friends. Therefore, to understand the burden of TB, this discussion will examine some of the key relationships for the nine affected individuals.

Women, primarily mothers, most commonly took up the role of primary caregiver. All nine people suffering from TB that were recruited for the study had female primary caregivers (see Table 17). This pattern is consistent with the literature on care giving of

those sick with any illness in Sub-Saharan Africa (Anarfi 1992; McGrath 1993; Ankrah et al. 1991; Muulu 2003; Ntozi 1997; Seeley et al. 1993). As can be seen from the case studies, four of the nine moved back to their mothers' homes for care when they fell sick with TB.

Table 17: Women as primary caregivers

Patient	Caregiver
Rocky	Mother
Alex	Mother
Molly	Mother
Innocent	Mother
Leo	Mother
Beatrice	Co-wife
Mukupu	Grandmother
Victor	Wife
Yvonne	Daughter

In the cases where the patient was a man, the caregiver would only go so far in providing care for that person, because traditionally it is not right for a mother to bathe her son or for a sister to bathe her brother who had reached a certain age. In Pemba/Batoka I noticed that, from the age of ten upwards, boys were expected to bathe themselves. At this age, they are considered old enough to do many tasks such as herd cattle or go to the market to buy or sell goods. In some homes, boys aged six used to bathe themselves.

Therefore, in households where the sick person was a married man, it meant that his wife took up tasks such as feeding, bathing and taking her husband to the toilet. In situations where there was no wife, male children took up the role, as can be seen in Alex's case.

Alex's son Joseph, aged 20, started bathing his father because the rest of the household would not do it. *"My brother and uncle George are not here most of the times, they are busy and, since the rest of the household members are women, they cannot bathe him or bring a tin for him to use as a toilet since he cannot walk,"* narrated Joseph.

Bathing Alex was a burden on some of the household members. No gloves meant no bath for Alex because his brother and his sons feared catching TB through direct contact with him. During some of my visit to his home, Alex complained about missing his bath, especially when the household had no gloves. *"I am usually isolated - they bathe me with gloves on and when they do not have gloves they either wear plastics or skip my bath."* The thought of being bathed with plastic gloves bothered Alex. This is a man who used to work in town, care for the family and bathe himself. Now that he was sick and weak, the inability to care for himself made him feel less of a man.

When Joseph took up the task of bathing his father and taking him to the toilet he was unhappy because it meant seeing his father naked. *"It is not right for me to see my father naked,"* explained Joseph. Although it made him unhappy, he would not stop bathing Alex because no one else would.

Indeed, TB was observed to cause emotional burdens on children. Some children had to take up the role of secondary caregiver. This trend of continuing with care giving, even though the care giving tasks were considered a burden, was common to all caregivers

In the first few months, before diagnosis and two to three months after diagnosis, the caregivers were hopeful and eager to see the patient well. They shouldered the burden of

care for the patient but, once their resources - both social and economic - became strained, the emotional and the psychological effects arose and relationships were affected. Similar anthropological studies (Bond 2006) reveal that extended family and community coping capacities may work well early in the epidemic. As it progresses, however, they often become overstretched and the social fabric of solidarity tears. "Sometimes the anger and depression expressed by people with AIDS, the hardships of caring for them with inadequate resources (no soap, towels or sheets, and water that must be carried) and the social stigma heaped upon them by neighbours, drive their families from them" (Vidal 1996 cited by Schoepf 2001). Therefore, over time, relationships become strained as people get tired of looking after the patient.

I should point out that it was not easy to see this tension in the first few visits to the households, because there was some form of what Chimwaza and Watkins (2004) call 'courtesy bias' - to complain about caring for one's close relative would, in this cultural context, be interpreted as a sign of insufficient love for the patient, or not wishing the patient well. But, as I spent more time with the families, I observed more of these tensions. To have a better understanding of how relationships become affected I will concentrate on Molly and Innocent's case.

When Molly and Innocent came home from Kitwe, their mother, Rachael, was very worried about her children and wanted them to get well. The day that Innocent arrived, no one at home went to sleep, the whole family was anxious and memories were still fresh in Rachael's mind as she recalled, *"I found him lying on a mattress, he was not able to talk or stand. You can imagine his body was stiff; his legs were not moving and his jaw too. He was very sick, I tell you this, he was very sick. I told the boys to prepare warm water to bathe him and his brother said they had already washed him."*

We prepared porridge for him to drink and in the evening we prepared warm water to wash him. No one used to help him in Kitwe. After washing his mouth and massaging it so hard he finally started to talk but we could not get what he was saying we would only hear him say, "mum". We prepared a bed for him to sleep. On that day we did not sleep, we sat

outside his room waiting for morning."

The above incident shows how family members can be supportive during the first months of illness or at (what they consider might be) the moment of death. Because they were very worried and wanted Innocent to get well, they kept vigil.

A few months after caring for the patients, the family members and the patients started to conflict. Nyblade et al. (2004:50) correspondingly note that, when parents find that the child they are nursing is not getting better, they will lose their patience and sometimes families say, "Because he is alive it is a burden to look after him."

Conflicts emerged as the illness continued. The worst conflicts were between the patients and their mother. Four months into treatment, Molly started complaining about her mother. By that time the family was having difficulty in finding money for food and transport. *"The problem is my mother talks too much. She complains about this and that. When you ask for food she shouts because there is no money at home,"* Molly complained.

Innocent too thought his mother talked too much. *"...other times my mother talks too much,"* he answered in response to my question about the care he was receiving. They both complained about their mother so much that, at one point, Molly moved out and went to live alone in the bush nearby; and she referred to her mother as a "demon".

"My mother talks too much. I think she is demon possessed. I suffer from high blood pressure so I do not like it when people talk too much. I quarrelled with my mother over cooking oil. On Saturday I was left home to cook and when my father came home and found me cooking he told my mother not to leave the cooking for me because he fears I might burn myself since am still weak. My mother got upset and when it was time to cook she complained that I had put too much oil in the food. She said that I was wasteful and was not going to have any cooking oil for a week. She said so many things about my illness - accusing me of having acquired the disease because of my carelessness. The words she used were too much for me so I failed to eat my food. I went to bed without eating. The

next morning I decided to move to that hut in the bush because I did not want to face my mother. She is a demon...

... Sometimes she says nasty things to my brother Innocent and he too runs away. One day I found him in the bush sleeping under a tree during those days I used to sell mangoes by the roadside. I asked him why he was sleeping under a tree, and he answered by saying he was running away from my mother's big mouth."

Molly and Innocent were not only having problems with their mother, but also with their siblings and the children at home. The others complained about the patients getting more food than they did. Close to end of TB treatment, when the friendships in the household were getting back on track, I was talking to Rachael and it was then that I realised that during the time of the conflicts she was emotionally stressed. She told me, *"I used to be so stressed and I would cry when I was alone. I ended up shouting at everyone and it made me sad that I would not handle my emotions. I know my children well and I can handle them but I was failing. Caring for the sick is not an easy task."*

It was not an easy task because many of the caregivers started falling sick themselves. During my visits some would complain of having headaches or general body pains. I could tell that most of them were over-burdened and fatigued. For instance, Rocky's mother fell ill towards the end of his treatment. Molly's mother too was ill twice during the course of fieldwork with what she claimed to be malaria. Yvonne's daughter and Victor's wife were both sick with what they too claimed was malaria. I say "claimed" because none of them visited the clinic for diagnosis but started self-treatment with drugs that they bought from the market.

Similar conflicts between caregiver and patient were experienced between Leo and his mother. At one point during the course of the study he ran away from home to live with his brother because he felt his mother was talking too much and was not caring enough. In the case of Beatrice, she and her co-wife used to argue a lot. One day I asked Enesia to share with me the things that worried her most. *"The most worrying for me is if this*

problem will ever go away,” she responded. I asked what her problem was and she said, “The patient is my problem. Is she going to be fine? I wonder every day. I am tired of looking for food for the patient. I cannot go to the field to pick pumpkins for my in-laws, when I do they give me some. However, I cannot go because I cannot leave the patient alone. She cannot manage on her own. She likes eating pumpkins but she cannot go to pick them and neither can I because of her. I have to collect water, she cannot do that. She cannot cook but she likes eating, so that is my problem.” Beatrice was seen as a problem, a burden, and this affected the relationship that she had with Enesia.

Apart from strain on relationships, and the caregiver’s physical wellbeing, it was observed that TB and HIV also caused distress migration. Distress migration in the sense that married patients were forced to separate from their partners due to TB. Alex and Leo found themselves in this situation: Leo moved from his wife and child, as can be seen from the case studies, to go and live with his mother. Alex, too, had to send his children to a relative because he was not able to provide for them, and also moved to stay with his mother whilst his wife (also sick) went home to her parents, leaving their home empty. This disintegration, as Muulu (2003:40) points out, may cause more psychological stress to the family members, especially the children.

Due to the above detachment from people suffering from TB, and the burden that came with looking after them, the patients experienced stigma from family members. In some cases the stigma was also experienced coming from friends and neighbours.

5.2 Stigma

Erving Goffman, who is widely recognised for conceptualising and creating a framework for study of stigma, described it as “an attribute that is deeply discrediting within a particular social interaction” (1963:3). His explanation of stigma focuses on the public’s attitude toward a person who possesses an attribute that falls short of societal expectations. He further explains, “The person with the attribute is reduced in our minds from a whole and usual person to a tainted, discounted one.” (ibid: 3).

What attributes did the nine people suffering from TB have that caused them to experience stigma? According to Goffman and other researchers, diseases associated with the highest degree of stigma share common attributes. Some of the common attributes that can lead to disease stigma are: moral judgements (see Bond 2006; Levine and Ross 2002); the fact that the disease in most cases is not well understood among the public; and the fact that the symptoms of the disease cannot be concealed.

In most cases, many people associated TB with HIV/AIDS in Pemba/Batoka. Some people believed that TB was caused by sexual intercourse (Corbett et al. 2003, Green 1999). Anthropological published literature on TB in Zambia is scant, but Adams carried out some work in the 1950s. His work (1950:14-50) looked at the concept of disease and African methods of curing disease. He surveyed a group of African students of Northern Rhodesia (now Zambia), regarding their individual and tribal concepts of disease. On tuberculosis, the study revealed that the students believed TB was caused by disobedience to the tribal laws and customs. One belief is that a man can catch TB if his wife has many lovers. To prevent it, the wife must not salt the husband's food herself; somebody else must do the salting for her (22). This belief persists amongst the Tonga and other groups today. During the course of my fieldwork, I came across many people who expressed ideas such as, "If one sleeps with a woman who is on her periods or someone who has aborted, that person is likely to be infected with the 'new TB'."⁴⁸ As mentioned by Sontag (1991:6), "Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious." In Pemba/Batoka TB was feared and was believed to be contagious.

In her study, Meira Weiss (1997) offers a symbolic analysis of the cultural construction and signification of three of the major "pandemics" of the late twentieth century: AIDS, cancer, and heart disease. Weiss's work is based on unstructured interviews conducted in

⁴⁸ TB that is associated with AIDS is referred to as new TB, bone TB, TB plus, and TB positive. While TB that is not associated with AIDS is popularly referred to as old TB, normal TB, TB of the blood, family TB, TB of the air, and TB negative (source ZAMBART- Social Science unpublished data).

Israel with 75 nurses, 40 physicians and 60 university students. In the findings on AIDS, Weiss states that AIDS was characterised by images of pollution. Pollution or contamination, Weiss notes, is powerfully presented in AIDS because AIDS is an epidemic of morality and stigma.

Seeing AIDS as a pollution, or a person with AIDS as polluted, explains why people who suffer from HIV/AIDS are stigmatised and avoided. Because of moral judgments attached to HIV and TB, and because all the nine people suffering from TB had noticeable symptoms that could not be concealed, some of them faced different kinds of stigma. The symptoms varied in each person; some were coughing heavily while others had lost a lot of weight – some displayed both. Some patients who had both TB and HIV had changes in hair texture that looked more like baby hair; some could not walk unaided, some looked so frail. The said attributes led the people surrounding the patient to see him or her as different from them.

5.2.1 Experiences of stigma

Nyblade et al. (2004:39) note four main types of stigma: verbal stigma, physical stigma and social exclusion, loss of identity, and loss of access to resources. I will focus on verbal, physical and social exclusion because these were the most common forms of stigma that some of the nine people suffering from TB experienced.

5.2.1.1 Verbal stigma

“Verbal stigma is stigma that manifests in verbal forms through gossips and rumours; labelling and expressing shame and blame; insulting, cursing, and scolding” (ibid:39).

Out of all the seven people that were co-infected with TB and HIV, Beatrice was the only one who had shared her status with a friend and, though it was not her intention, other people in the community came to know about it. I was in the hair salon chatting with the women and it was from there that I first realised that other people in the area knew about

Beatrice's HIV status. Apparently, Beatrice had gone to the village next to hers to visit a friend. While there, she whispered her status to a friend, her friend shared it with a friend and then most of the women came to know about it.

As I sat in the salon, one woman asked me to confirm if Beatrice was positive or not. I kindly told her that I did not discuss the families that I visited. I further informed her that if the families wanted to discuss with other people what we talked about they were free to do so. One woman said she wished home-based caregivers would do the same. All the women agreed to this and some started giving examples of incidents that had occurred in the community where home-based caregivers breached confidentiality.

The topic in the salon shocked me, not because I did not know the HIV status of Beatrice but because other people had come to know about it so quickly. Beatrice's status was known, not only from the gossip, but also because people used to see her going to the Liabi Support Group⁴⁹ meeting every Tuesday afternoon.

All the nine people reported widespread gossip and rumours in their neighbourhood. Some, like Rocky, had been insulted openly by neighbours and called names by a young boy in the community, who took advantage of Rocky's loss of physical power.

"The other day, a young man from that house (he points to his left) came to accuse me of stealing his chicken. I went to sell a chicken that my mother was given by a relative. Therefore, when he saw me he started saying that the chicken was his. I tried to explain to him but he started shouting on top of his voice that a TB patient had stolen a chicken! He called me all sorts of names. I was so upset. If only I was fit, I would have hit him hard! He is lucky I am sick. How could he accuse me of stealing his chicken?"

On that day, my mother was not feeling very well but anyway she came out and tried to talk to him. Everyone came to watch. I came back home and then later in the afternoon the

⁴⁹ Note that this was the only support group in Pemba and the first of its kind for people living with HIV.

grandmother to the young man came to apologize. I accepted her apology because she is an old woman. I know the boy is not sorry because he did not come here himself."

"You said he called you all sorts of names. Do you mind telling me about those names?" I probed. Rocky went on to explain, *"He called me an AIDS patient. He called me a dog. He told me that it was not his fault that I was promiscuous and had landed myself a disease."* Rocky was quiet for some time and I wanted to know what he was thinking about so I asked him, "How did that make you feel?" *"I felt very bad. I still feel very bad. That young boy has no respect. He insulted me in front of my children. Anyway I have left everything in God's hands."*

Rocky's case was not unique. Apart from Yvonne, Mukupa and Alex, the rest of the participants reported having experienced verbal stigma and were in some cases blamed for bringing the disease upon themselves. I suppose Yvonne never experienced verbal stigma because of her epilepsy problem, she was always known to be a sicklier around the community such that, even when she was suffering from TB, some of the people might have concluded she was suffering from her usual sickness. Alex, on the other hand, was bedridden - so he rarely came into contact with people. Mukupa never discussed her HIV status openly (see Effects of Stigma for details) and, if she had ever experienced verbal stigma, she never shared it.

To illustrate verbal stigma, Bond et al. (2004) over a space of two days collected 104 terms in Lusaka and 64 terms in rural Choma. The 168 terms were used by people in the named communities about people infected with HIV and TB. On the terms collected she reports, "Although some terms reflect how people have accepted the existence of HIV/AIDS, most of the terms are harsh and negative with strong moral overtones and, occasionally, black humour. There were no terms that were sympathetic." (2004:17). As Lock and Scheper-Hughes (1986:137) explain, "The rub is that the metaphors, the cultural images and representations of the 'master' diseases of our time - cancer, heart disease, AIDS - are more ugly than sublime, more degrading than elevating, more exploitative than consoling." Her point is that the societal and cultural responses to disease create a second illness in

addition to the original affliction, which she calls a “double”.

5.2.1.2 Physical stigma and social exclusion

Apart from verbal stigma, some of the nine people also faced physical stigma. Physical stigma includes distancing and avoiding contact with people affected or infected. “Accompanying physical exclusion comes social exclusion and loss of one’s identity in the community.” (Nyblade et al. 2004:45). This entails a situation where people affected by the disease might be prevented from participating in family life and experience a reduction in daily social interaction.

Physical and social exclusion was experienced among all the nine patients, not only within the household but also by their neighbours and friends. *“I remember when Innocent came from Kitwe, he was very ill and all my mother’s friends only visited once and never returned,”* Molly explained when I asked her how their neighbours and friends were responding to her and her brother’s illness.

In some extreme cases, some neighbours stopped their children from visiting the affected households for fear that their children could be infected with TB. This was observed in Molly, Beatrice, Alex and Rocky’s households. Whenever I visited the households, I noticed that, unlike the children at the comparative households who used to run around in the nearby bush, collect fruits and play house with neighbours, children in the affected households could be found at home most of the time.

At first, in Rocky’s case, I thought the children were saddened by the father’s illness and that is why they were always around him. I later came to learn from Rocky that, apart from being sad that he was ill, his children were unhappy because they had no friends. The neighbours stopped their children from playing with his children because they feared their children would catch TB from him. Through losing friends due to TB in the household, the children were deprived of the joys of friendship.

In addition to being avoided by friends and neighbours, it was observed that, within the confines of their families, the patients were being isolated so that physical contact with them was minimised. Utensils were kept separately and it was often suggested that the patient takes meals separately for fear of infection. *'They fear that if they stay near me they can get TB so they stay far away,'* Mukupa narrated. Apart from Beatrice, all the rest were given separate utensils. But for Beatrice too, this was soon to change.

In Beatrice's case, her co-wife and her husband were supportive and Enesia took her in when she was just suffering from TB, but when they were tested for HIV⁵⁰ and Beatrice was found to be HIV positive, the situation changed. Mubanga blamed Beatrice for his HIV status and accused her of infecting him with HIV. Enesia, on the other hand, stopped helping Beatrice with any chores and unlike before, refused to go near her or to eat with her.

"I cannot infect anyone at the moment but my co-wife does not think so. She has been giving me food separately from the time I started getting worse. She is scared that I might infect her and the children. Sometimes, I get so weak from the diarrhoea and I cannot wash my clothes. Sometimes, I am too weak to get up and run to the toilet so I end up messing myself. She refuses to help me. I wish I would go home to my mother but I have no money. She refuses to come near me and when it is time to eat, she leaves the food by the door. She tries to avoid any contact with me. I feel very bad," Beatrice narrated in between sobs.

Enesia, on the other hand, had this to say about the way she treated Beatrice, *"We decided that she should eat alone because when she washes her clothes she does not use gloves. She uses bare hands. Those are the same hands, she uses to eat; therefore, she will eat alone. I do not want her to infect my children with HIV."* Mubanga and Enesia later chased Beatrice from their home.

⁵⁰ All three were tested, Beatrice was positive and so was Mubanga while Enesia was negative.

Leo also faced stigma related to HIV when his half brother forced him to sleep under a table. In addition to this, Leo's wife left him when she found that he was HIV positive (see Case Study 4A). All the people co-infected with TB and HIV were viewed as members of a risk group; polluted carriers of an evil disease who should be avoided and punished for their misconduct, deviance, and delinquency (Weiss 1997:465). It is no wonder that some family members did not want to mix with them.

5.2. 2 Effects of stigma

The social exclusion that some patients experienced due to TB caused them to hide their HIV status. Two of the nine, Beatrice and Mukupa, had feelings of anger and distress about their HIV status. Unlike Beatrice - who talked openly about her HIV status - Mukupa found it hard to do so. For Mukupa, these feelings of anger and distress resulted in complete denial of her HIV status. She refused to accept her status and never allowed any one to talk to her about HIV. My research assistant and I had tried during the first months of fieldwork to bring up the topic, but Mukupa never responded to anything to do with HIV. She was happy to talk to us about TB but not HIV. We came to respect her wishes and throughout my stay in Pemba/Batoka I never discussed HIV with Mukupa. Nevertheless, we asked her counsellor from ZAMBART to help her come to terms with the disease.

Six out of seven people that were co-infected with TB and HIV did not share their HIV status with friends, neighbours or church members because of fear of stigma attached to the disease, considering that AIDS is a disease associated with immoral behaviour. As Lock and Scheper-Hughes (1986:137) state, "The disease and its double force the patient, now twice victimized, further into the cage of his or her illness: shunned, silenced, and shamed in addition to being very sick." For three out of the seven co-infected, the fear of sharing their status extended not only to friends and neighbours but also to family members that they were living with.

“Have you hidden the fact that you are HIV positive from your parents and family?” I asked Innocent. *“Yes I have not told them my status,”* he replied. He further explained, *“I do not want to share with them because they talk too much. My mother talks a lot and she will tell everyone who comes that I am an HIV patient.”*

Alex too was uncomfortable with sharing his status with his family. For Alex it was not because of gossip, he feared disclosing his HIV status because he thought his family would shun him. When asked why he had not shared his HIV status with his family, Alex responded, *“I feel it is not the right time to tell them about my HIV status. I think that when I do, they will fear and shun me. Already they are not so free with the knowledge that I am a TB patient; HIV will only make it worse.”* Being diagnosed as a TB patient caused distress among his family members, and they had serious difficulties accepting it, so he thought telling them his HIV status would only make matters worse.

Whether or not the co-infected people disclosed their HIV status, what I came to learn - especially from Beatrice’s incident in the hair salon - was that when people suspected someone had HIV they did not want to tell the patient that they knew. Some of the relatives and friends developed an intense interest in discussing the patient’s health with me and my research assistant, or with the household counsellors from ZAMBART, in the hope of making us reveal what they thought they knew. I remember Alex’s brother asking us why Alex was drinking a different type of drugs from his wife. *“My sister in law and my brother drink different medicines but aren’t they both suffering from the same AIDS?”* Alex told his brother he was suffering from TB. Never at one point did he mention to his brother that he and his wife were HIV positive.

The effect of stigma on the patient was devastating for both men and women, but at this point, I will concentrate on the men because they were more affected than the women in the sense that the men were used to being the providers. On one of my visits to Victor’s house I found him lying outside on a sack listening to the radio. Tamara, his wife, was not around. During my conversation with him, I asked him where his wife had gone. Victor replied, *“She has gone to do some piecework. We still have some maize left for busu*

(maize meal) but there is no money for cisyu (relish)... I wish I was much better so that I would provide for my family, you see, my wife is now doing my job. It makes me feel less of a man. I am supposed to be a Tonga bull⁵¹." He stared in the sky, as if talking to himself.

During my fieldwork, I came to see more men cry because of what they were going through. They had lost their self-esteem and expressed their powerlessness by referring to themselves as a "child". The common phrase by all was, "I feel like a child." Rocky once told me, *"I am like a child who needs to be cared for throughout the day that it has also disturbed my mother's business."* Leo too felt like a child. *"I feel like a child because everything is done for me by my mother."*

The thought of being cared for like a child affected the patients emotionally. This resulted in a lot of crying, especially in men who culturally are taught to be the providers and not the receivers. Leo, Alex and Rocky broke down on many occasions during my visits to their households. Their crying affected me too - many times I felt like crying with them because I had come to learn and know their suffering, but I always restrained myself.

To find meaning or an answer to their suffering, some of the participants turned to God. Rocky, Molly and Yvonne delved further into Christianity. *"I think God is the one who made me like this so that I can change my bad habits like smoking and drinking,"* explained Rocky. Molly too believed more in God. *"No problem, I only pray to God to help me. If God wants, I will die,"* she explained. On most visits, we used to find her reading the bible.

In conclusion, I would like to highlight the main points of the chapter. The care of TB

⁵¹ The men in Pemba/Batoka, and Tonga men generally, pride themselves on characteristics displayed by the bull in the herd i.e. it leads the way when grazing. Wealth in Tonga land is measured in cattle terms. It follows therefore that manliness and power is seen through the ultimate measure-cattle. Therefore, the bull (*mucende*) is a symbol of power, authority and manliness [also sexual prowess].

patients fell on female kin – mainly mothers. In the first weeks of illness, patients were given all their attention and support, but as the illness progressed and resources became scarce, patients were seen as burdens. Caregivers were often overstretched, and exhausted, and ended up ill themselves. Secondly, children frequently had to take up the role of secondary caregiver, bathing and feeding their parents. Thirdly, the nine people suffering from TB experienced stigma within and outside the household. The most common forms of stigma experienced were verbal stigma and social and physical exclusion. Lastly, some relationships broke down because of the TB illness, and male patients were often reduced to tears and suffered from low self-esteem.

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CHAPTER SIX

OUTCOME: TIPPING OR TRANSFORMATION

6.1 Introduction

Tipping is associated with words such as tilt, lean, angle incline, and slant (Collins Dictionary 2008). When authors (Ahlburg DA 2000; Chambers 1983; Farmer 1999, 2000; Killewo 2002; Kamolrantanakul et al. 1999; Ogden et al. 1999; Rajewsari et al. 1999), discuss how TB may push already poor households into deeper poverty and vulnerability, I imagine the situation in my head as tipping - tilting from a lower stage of poverty to a deeper one, falling from one state of poverty to the next. Chambers (1983) calls this process a poverty ratchet. This was not lost on the people of Pemba/Batoka.

When I asked my informants in Pemba/Batoka about the Tonga words that denoted tipping, words such as *kuchincha*, *kusumpuka*, *kuwa*, *kuvbuba* and *kucetaala* became interchangeably used. The word *kuchincha* is synonymous with the English word “change” and did not imply any judgment on the type, direction or meaning of the transformation. Other words such as *kusumpuka* were identified to mean “progress”, which is change for the better. *Kubvuba* means “becoming wealthy”, a change that leads to richness. *Kuceetala* literally means to become poor, a degeneration, from good to bad, from wealth to poverty.

When I further asked about change that comes with illness such as TB and HIV, *kuwa* was the word that many of my informants identified as relating to the change that comes about due to illness. *Kuwa*⁵² plainly means falling. It denotes a critical change in someone’s life.

⁵² *Kuwa* originates from the verb *wa*, which means to *fall* (Keenan 1992:116). *Kuwa* is a verb in its singular form. When used in its plural form, the Tonga verbs, unlike the English plurals that are formed by adding ‘s’, are changed by adding a prefix at the beginning of the sentence. In this case *kuwa* (singular form) changes to *bakawa* (plural). When used in the first person, the singular form *ndakawa* (I fell) is used in the past remote sense, whilst *wakawa* (he fell) refers to the second and third person. The *bakawa*, *twakawa* (we fell, they fell) is used in reference in plural to refer to others.

Moreover, it happens fast because it is something that is not planned. Indeed, it is difficult to predict and prepare for HIV/AIDS and TB (Rugalema 2000). Some of the patients, especially Leo, had used this word to refer to their current status - particularly when he recalled how comfortable he was before his illness, only to be reduced to a point where he had to beg for food.

“Ndakawa ba sis, ndakawa,⁵³” he would say. *“I used to earn about K300 0000 per month that is before I remove money for food. I am the breadwinner, everyone looks up to me but now things are tough. My sisters are married but the problem is that the one who used to help my mother is having problems with her husband. All the family used to look up to me. I used to care for my mother - as you can see she has not even started farming (he points to the field next to the house) - it is because there is no money.”*

From the focus group discussions I held with elderly people in Pemba and with neighbourhood health committee members from Pemba, Batoka and Kasiya, I learned that *bakawa* is usually used to refer to people that were at one point wealthy or comfortable but later became poor. According to these groups, chronic illness such as TB and HIV and disabilities, laziness, poor planning, having too many girlfriends, Juju wealth⁵⁴, careless spending and too many dependents can lead to moving from higher status in society to a lower one. Tipping, therefore, was usually used as a change in a negative sense.

I used to ask my informants about the opposite of tipping, and words such as *kusumpuka* and *kuvbuba* would come up - though they told me that such a change was very rare in the community due to many “new TB” related deaths. *“All the people I know who tip due to illness never transform,”* Pretoria once said to me. Transformation in this thesis means a makeover, or a renovation to make anew. Therefore, contrary to definitions of tipping, transformation is change in a positive sense.

⁵³ I have tipped my sister, I have tipped!

⁵⁴ Juju wealth is wealth believed to have been acquired through witchcraft

In the penultimate chapter, I look at the outcomes and futures of the nine people who suffered from TB. The main question in this chapter asks: What was the outcome of TB for them and their families - did the convergence of TB, HIV and food insecurity lead to tipping as I anticipated it would, and how did people cope with this convergence?

To answer these questions, the chapter begins by looking at Alex and Beatrice who died, before moving on to focus on those who survived. I divided those who survived into three emerging categories: people who were suffering from both TB and HIV and on ARV treatment; people who were suffering from both TB and HIV but not yet on ARV treatment; and people who were exclusively suffering from TB. By analysing the lives of the people in the above categories, the chapter explores whether tipping took place.

6.2 Death

The event of having a TB patient in a poor household can be devastating, especially if the TB patient is also HIV positive (Garrett 2000; WHO 2000). Although HIV affects the whole population, it is often the poorest of society that are most vulnerable to the epidemic and for whom, if the TB/HIV patient dies, the consequences are most severe. Death reduces assets, income (with the loss of a productive member) and leads the household into debts, further impoverishing them (Barnett and Blaikie 1992; Barnett and Whiteside 2006; Munthali 2002).

The above consequences of TB/HIV death will be explained by looking at two⁵⁵ out of the nine people suffering from TB who died during the course of the study. I will first start by looking at the lives of the two people close to death and the costs incurred during that time, and then move on to talk about the funerals and the funeral costs. Lastly, I will look at the lives of the families after the death of the TB two patients.

⁵⁵ Alex and Beatrice

Alex:

It was on 1 November 2006 when Alex became very ill; he had developed bedsores since he rarely moved from his bed. His stomach and face were swollen - growing bigger by the day. Because he was not showing any signs of improving, his family took him to Chikuni Mission Hospital - a Catholic mission hospital. Alex's family thought they would get better services there than what they were getting from the government clinic.

George, Alex's brother sold four chickens and a goat to raise funds for Alex. He sold each chicken at K10 000 and the goat at K45 000. The money raised was used to buy fuel. A man who owns a car in Pemba agreed to help with transport on a condition that Alex's family bought the fuel. At Chikuni, Alex was admitted for four days before being referred to Monze Hospital for further examination. A vehicle owned by the hospital was used to transport Alex to Monze on 5 November 2006⁵⁶. The next day Alex died. His body was transported back to Kasiya for burial.

Transporting Alex's body from Monze to Kasiya cost K100 000, and the coffin was bought at K150 000. According to George, the family spent about K100 000 during the time Alex was admitted in hospital on food and other needs, and K400 000 during the funeral. The K400 000 was used to buy items such as cooking oil, salt, vegetables, etc. To raise the money George borrowed from his friends and neighbours since he had very little livestock left to sell⁵⁷. Alex's uncle, who lives in Monze but was in Kasiya to attend the funeral, also contributed K100 000.

On 7 November 2006, Florence and I went to the funeral house to pay our respects. From afar, we heard people crying. As we approached the house, the crying grew even louder and some people came to welcome us. We headed for the grass-thatched hut where Alex's mother, wife and sisters sat with some other women. For the first thirty minutes the weeping did not stop. There was a really sad atmosphere and I wished I had known Alex

⁵⁶ The mission hospital provides free transport for referrals

⁵⁷ He had sold and killed most of his livestock during Alex's illness.

better when he was in good health because the mourners kept saying how great Alex had been to them. One man kept shouting out, "*The bull has gone, the great bull has gone!*" Some women were saying, "*You were a good man and you always provided us with all we asked from you.*" One woman kept asking, "*Alex! Who do you think will take care of your children? Please come back because they still need someone to take care of them!*"

After the crying had stopped, we had a chance to talk with Alex's mother and his wife. Alex's mother told us she was worried about the children that Alex had left. "*I do not know what will become of Alex's children; I am too old to look after them. I cannot afford to provide for them.*" She also complained about the lack of food to feed all the people that were gathered at the funeral house. "*There are too many mourners and we have nothing to feed them,*" she said.

After talking to Alex's mother and wife, I went outside to talk to the women who were cooking. I observed that the family had used up almost all of the maize that was stored in the maize stores (*butala*). When I asked how the maize was used, the women explained that they had taken some for grinding so that they could have some maize meal, a portion was used for *chibwawntu* (local sweet beer) and the rest was cooked. At the time of visit, everyone was served cooked maize grains and I was informed that it had come from the *butala*.

Apart from using up all the maize, the family also had to kill some of their livestock. In Pemba/Batoka, the family of the deceased is traditionally obliged to provide the mourners with a cow. The cultural norm is to slaughter at least one cow at the beginning of the funeral and one cow at the end of the funeral. The flow of blood is a sign of washing away evil spirits. Where the number of cattle owned allows, several may be slaughtered during the mourning period. In the absence of cattle, goats may be slaughtered and in the absence of both cattle and goats, chickens are slaughtered. In poor families in Pemba/Batoka, goats and chickens are slaughtered. Hence, in Alex's case, the family slaughtered four goats during the funeral, two of which were from George's stock, and the other two were a gift from the neighbours. The neighbours and friends also contributed some money to the

bereaved family.

During the funeral, it is a traditional practice for men to sit and sleep outside while the women sit and sleep in the house/huts. An elderly friend of mine once explained to me that the main reason why men sat and slept outside in the olden days was because they had a role of protecting the corpse from wild animals, which they kept in the hut. “*There were no mortuaries in those days*,” he explained. The women and the children slept indoors for the same reason. The sitting and sleeping arrangements during the funeral have been passed on from generation to generation and, though there are now very few wild animals to attack the corpse or the mourners, people still do it as it was done many years ago.

Therefore, after I had finished chatting to the women I walked over to a tree where the men sat. The men wanted to know if the widow was HIV positive or not so that a member of the family could inherit her. There was one man who kept insisting that the woman undergoes sexual cleansing⁵⁸ because, traditionally, it was a right thing to do. We concluded that he was an interested party in the cleansing because he insisted on knowing the HIV status of the widow. However, we clearly explained to him that we were not there to discuss people’s status.

⁵⁸ Malungo (2001:377-378) specifically looks at the traditional practices of sexual cleansing (*kusalazya*) in Zambia, specifically Southern Province. In Southern Province, it is believed that when a person dies two spirits remain, one the *muzimo* and the other *ceelo* (*zyeelo* in the plural) or *musangu* (*basangu* in the plural), the ghost (Colson 1962). Living people do not wish for the dead person’s spirits to trouble them. For this reason, upon the death of an adult, the ritual of *kusalazya* is enacted. In the olden days it was a must that someone have penetrative sexual intercourse with the spouse of the deceased in order to chase away the spirit of the dead from the living partner. Today, mostly likely due to HIV, there are other alternatives such as sliding over the widowed spouse, or the use of herbs. “A widowed person who is not cleansed is generally regarded as an outcast.” (Malungo 2001: 372)

We learned from the chat with the men that Alex's uncle (who had contributed K100 000) was unhappy with the family's decision to transport the body from Monze to Kasiya. His idea was to bury Alex in Monze since it was cheaper than hiring a car to transport the body. However, the other family members refused and insisted on taking the body to Kasiya.

A month after the burial, we asked Alex's mother why she preferred her son buried in Kasiya even though it was an expensive venture. She explained that it was the right thing to do because that was his home, his late father who was a chief in the village was buried in Kasiya at the same site where they buried Alex, and so were some of Alex's relatives who had died before him. During the same discussion, Alex's mother and George revealed that they had many debts to pay that they had not cleared from the time of the funeral.

Note: Alex's wife was not sexually cleansed because Alex mother insisted that no man was going to have sex with her daughter in-law. I suspected she had an idea of her son's status. Alex's wife narrated the cleansing process, *"It was done early in the morning. I was told to lay down, half-naked and my mother in law slid over me. After that, she took me for a bath. She bathed me and that was all."* According to Malungo (2001), this kind of cleansing is now practised by some people as an alternative to sexual cleansing with the hope of reducing HIV transmission.

Beatrice:

Around 16:00 on Sunday 13 May 2007, Beatrice had a black out, and fell to the ground and hurt herself on the chin, mouth and head. Her body was shaky, cold and weak. When she awoke an hour later, she was still very weak and it was then that her husband, Mubanga carried her on a bicycle to Pemba Clinic where she was admitted.

On Tuesday when I passed through the clinic to visit, Beatrice was not talking much. She greeted me, but that was all. There were two other women admitted in the ward, one was fast asleep and the other was eating a banana and she had a bottle of Fanta with some food on top of her locker. Beatrice, on the other hand, looked so weak and lifeless - there was no

sign of food by her bedside, on top or inside the locker. Beatrice's sister, a 39-year-old woman who looked much older than she was, had come from Batoka to look after her. She was helping Beatrice with everything she needed, such as going to the toilet, eating and bathing. I asked the sister if Beatrice had been given anything to eat. She said she had cooked some *insima* for her but she refused to eat because she wanted fruits and soft drinks. Beatrice's sister had no money to buy soft drinks and fruits so Beatrice ate nothing until the evening when Florence and I took her some fruits.

On Wednesday 16 May 2007, Beatrice's condition worsened. The clinic staff said it was better for Beatrice to go to Monze Hospital. Beatrice did not manage to get to a hospital because the sister had no means of raising funds to book a taxi to transport Beatrice to Monze Hospital. She died that evening.

It should be noted that although Beatrice was practically Mubanga's wife, traditionally Beatrice's family did not acknowledge the marriage since Mubanga had not paid any bridal price (*lobola*) to her relatives. So when Beatrice died, though she was nursed and cared for during much of her illness by Mubanga and Mubanga's first wife Enesia, the funeral would not be held at Mubanga's house. Beatrice's relatives demanded that Mubanga transport the body to Batoka so that the funeral could be held in Batoka. Beatrice's three children, mother and sisters live in Batoka. The interesting point was that though, Beatrice's relatives had demanded the funeral be held in Batoka, they refused to buy a single thing for the funeral house. Mubanga was told to buy all funeral requirements. He was ordered to transport the body from Pemba to Batoka, buy food for the mourners - such as maize meal, cooking oil, salt, sugar, relish, a goat or cow - new clothes for Beatrice, a white cloth and a coffin.

When I later asked Enesia what she thought about the demands she said, "*The relatives were demanding for so many things. In a way, they wanted to punish my husband for taking Beatrice as his wife without paying lobola. We explained that we could not manage to get all the things they asked for but they said they wanted all the food and Beatrice's body with all her clothes by the end of Thursday.*"

Mubanga and Enesia had no choice but to look for the money. They also faced many problems after Beatrice's funeral because her relatives refused to cleanse Mubanga, as can be seen from Enesia's story:

"We went flat out to look for money. We borrowed a K150 000 for a coffin. My husband went to ask the man who works at the priest's house for some money and I went to see my father who gave me K250 000. In total we raised K700 000. Booking a vehicle to Batoka cost K150 000. We asked the driver to be kind and reduce the price and he reduced by K20 000. We bought cabbage for K40 000, cooking oil five litres worth K36 000 and four bucket of maize worth K50 000. My parents gave us some maize, my husband's brother gave us a goat, and two of my husband's nephews brought two chickens and some beef.

Friday morning we took the body to Batoka but the relatives refused to go ahead with the burial unless we produced K600 000. We explained that we had no money but they responded by saying, 'If you have no money, take back the body to Pemba! You only come back after you raise the money.' We started negotiations, it was a long process and we were all tired. They wanted my husband to pay that money because he had not paid the bridal price and they felt like he had killed their relative. Finally around 14:00 hours when my husband gave them K100 000, they agreed to the burial. We told them the body would start smelling if we keep it for another day. After the burial my husband was detained and he could only come home after the K600 000 was paid.

When we came back, we informed my father-in-law. He was worried about his son. He sent one of his sons to Batoka to talk to Beatrice's relatives. He told him to go and explain that my husband was the only one who could look for money, so by holding him they were wasting time because finding money would take even longer. The following day my husband came back, home. We raised K200 000 and sent it to Batoka and asked Beatrice's relatives to pardon us because that was the only money we could find. We also sent a word for them to come and cleanse my husband but they did not respond and they have never been here.

Those people are bad; imagine the amount of money we spent on their daughter while she was ill. We tried to explain all that, but they did not want to hear a word of what we were saying. Their daughter was very demanding, we tried our best to provide for her, and this is how they can repay us. We waited a few days for them to come and cleanse my husband but they did not come. My father-in-law organised local people to come and cleanse my husband and our home.”

6.2.1 After death

The above cases show two different experiences of two different patients, but offer a similar pattern and series of consequences for the patients and their families. These TB/HIV consequences were experienced as a tipping mechanism in these households.

I always wondered if Alex and Beatrice’s deaths could have been avoided had they started taking the ARVs on time. In the previous chapter, I mentioned that Alex knew his HIV status before he found out that he was suffering from TB but he could not raise funds for his transport money to the ARV clinic. Beatrice too was willing to visit the ARV clinic for further examinations but her husband delayed giving her transport money such that she started taking the drugs late. This delay, due to financial constraints, meant the patients missed the opportunity to start ARV drugs - drugs that would have prolonged their lives. For these two patients there was no hope of transformation that ARVs can bring about.

Both Alex and Beatrice’s children had lost a parent. Like the mourners at Alex’s funeral had rightly asked, who was going to take care of these children? A few weeks after Alex’s funeral, we visited his wife and she was complaining about lack of money to send the children to school. *“I am facing a lot of problems. Schools will open soon but I have no money to send my children to school.”* Several months later and up until the time I finished my fieldwork, the children were still not in school. Alex’s wife was actually planning on taking her children to her mother’s home in Kapiri-Mposhi with the hope of them having a better life there, because she could not manage to care for them. If the outcome of TB is death, the negative impact of TB stretches beyond the illness.

A similar study carried out in two districts of Zimbabwe in 2000 discovered that, after the death of their parents; grandparents, other older relatives and extended family might foster surviving children. The study further discovered that these children are less likely to attend school (UNAIDS 2005). Similarly, a study in South Africa suggested that households where an adult had died from AIDS were four times more likely to dissolve than those where no deaths had occurred (Hosegood et al. 2004).

Alex and Beatrice's situations also offer an insight into funeral costs. All households that participated in the study were given an expenditure sheet to record everything that was bought from beginning of month until the end of the month. From the data collected we learned that normal monthly expenditure for non-affected households never exceeded K50 000 unless in January when they bought school requirements for children and in October and November when they bought farm implements. See an example of an expenditure list of a non-affected household in Table 18.

Table 18: Expenditure list for comparative household to Beatrice's household

May 2007: expenditure for comparative household to Beatrice				
What was bought	Quantity	Cash/Credit	From where	Price
Salt	1 packet	Cash	Pemba Town	K1000
Meat	1kg	Cash	Pemba Town	K8000
Sugar	1 packet	Cash	Pemba Town	K3500
Washing paste	1 packet	Cash	Pemba Town	K2500
<i>Rape</i>	5 bunches	Cash	Pemba Market	K1000
Maize	Half a sack	Cash	A neighbour	K20 000
Cabbage	1 head	Cash	Pemba Market	K2000
<i>Saladi</i>	1 bottle	Cash	Pemba	K5000
<i>Kapenta</i>	2 packets	Cash	Pemba Market	K2000
			Total	K45 000

Table 19: Summary of funeral costs for both Alex and Beatrice

Alex's funeral expenditure		Beatrice's funeral expenditure	
Task	Cost	Task	Cost
Transport to Chikuni Hospital	K100 000.00	Coffin	K150 000.00
Food and other requirements during admission	K100 000.00	Transport body from Pemba to Batoka	K130 000.00
Transport body from Monze to Kasiya	K100 000.00	Cabbage	K40 000.00
Coffin	K150 000.00	Cooking oil	K36 000.00
Food during funeral	K400 000.00	Four buckets of maize	K50 000.00
		Total payment to in-laws	K300 000.00
		Transport from Batoka to Pemba after funeral	K30 000.00
Total	K850 000.00	Total	K736000

Comparing the total costs for Alex and Beatrice's funeral expenditure (See Table 19) and the total monthly expenditure for the comparative household it is easy to see that funeral costs are much higher than a normal monthly household expenditure in a poor rural setting. Because the funeral costs were more than 16 times the normal monthly costs, to survive, the families resorted to borrowing and selling of livestock, as was seen in the previous chapter. What was observed was that debts begin to accumulate long before the patient actually dies and are likely continue long afterwards. By the end of my fieldwork, both families had not yet paid off their debts.

Apart from debts that accumulate due to funeral costs, the funerals also contributed to the food insecurity of the households. In Alex's case all the maize that his family stored to use over a period of time was used during his funeral, leaving the family with nothing to eat after the funeral. It is also important to keep in mind that the household would struggle to buy more maize after the funeral because they had no money left. Furthermore, they had already borrowed from neighbours and friends and so it was difficult for them to continue

borrowing. Barnett and Whiteside (2002: 239) also note that HIV/AIDS affects food security and it results in a severe decline in the insurance value of social networks. "The sicker your family member becomes, the more money you may have to borrow from relatives and friends, the more you may seek their assistance. In the end, they say no more."

I agree with Barnett and Whiteside's statement: I observed that family members and friends were more helpful during the funeral but not during the illness period and after the funeral. One interesting thing to note is that when the patients were ill it was the female friends and relatives who were helpful⁵⁹, but I saw a change in these roles when the two patients died. During the funeral, the men were at the forefront to offer assistance. For instance, Mubanga's father and Mubanga's nephews did not assist Mubanga's household during Beatrice's illness but, when she died, they contributed money and food. Similarly, Alex's uncle from Monze did not offer any assistance during Alex's illness. After the funerals I saw this help slowly disappear; a visit to both households after the funerals revealed that there was no longer help coming in from the male relatives.

In relation to food security, in both cases livestock was sold to raise money and to feed the mourners. Findings obtained by FAO (2002) in Caprivi and Oshana - two communal area farming regions located in the Northern part of Namibia - indicate that a common strategy for covering direct costs associated with sickness and death is the sale of livestock. The sale and slaughter of livestock to support the sick and to provide food for the mourners at funerals does not only endanger the livestock sector but also crop production, due to reduced availability of draught power. This in turn can exacerbate future household food insecurity.

In addition to the above, Alex died at a time when people in Pemba/Batoka were preparing fields for 2006/2007 farming season, and a few had started planting maize. Thus, Alex's death affected his family in the sense that while they were mourning, others were busy

⁵⁹ This situation was not only observed in Alex's and Beatrice case, but in all the nine patients.

working in their fields. The funeral and costs attached was also a disturbing factor to Alex's relatives in terms of food security because, after the funeral expenditure, they had no money to buy farming implements.

On 16 May 2007, on a visit to Alex's mother's house, she complained about the poor yield of maize that farming season. She explained that there was no food at home and that all they had been eating throughout the previous week was pumpkin leaves. I asked her what she was going to do, since the poor harvest meant lack of food the whole year. She informed me that those people with poor yields for whatever reasons had a community meeting. At the meeting it was agreed that they write down their names and then the chief would see what to do about it.

Alex and Beatrice's cases are typical examples of what poor rural households experience when faced with HIV/TB related deaths. The cases show very clearly that HIV/TB related deaths in a rural poor household impose significant financial burdens on those affected, many of whom are least capable of bearing these costs, leading to what Ogden et al (1999:856) call "personal and family indebtedness". HIV/TB related deaths in both cases lead to tipping as costs intensified, stripping families of their livestock and food.

6.3 Suffering from both TB and HIV on ARV treatment

Antiretroviral therapy (ART) is not a cure for HIV, but successful use halts the decline in immune deficiency and prevents disease progression. It helps to delay the onset of dreaded AIDS that caused Alex and Beatrice's death.

Mogensen (2005:7) writes about how the costs associated with ARVs have the potential to making people poor, but at the same time also have the potential to do the opposite. At this point it is the potential to do the opposite that I want to focus on. Although four⁶⁰ of the co-infected people who managed to start taking ARVs were pushed into deeper poverty by borrowing and selling off livestock, I came to appreciate how effective ARVs can be as I watched three people living with HIV rise from the brink of death back to life. I saw ARVs help transform the lives of these three in terms of physical appearance, economic activities, social relationships and social networks.

Most comforting for the three and their families, is that all three started to look healthy once more. At the start of my fieldwork the three were bedridden. They constantly fell sick and complained about different parts of their bodies that were hurting. Sometimes it was swollen legs, stomach pains, headaches, or ears; and other times it was just general body weakness. Due to these numerous complaints they used to visit the clinic at least once or twice a week; but after starting ARVs, I saw a reduction in the complaints about body pains and a reduction in the number of visits to the clinic. Although in the first month of starting ARVs they complained about the side effects (Molly vomited and had a stomach upset the first day she took ARVs, Leo had swollen glands, while Innocent complained of swollen legs and a rash), these slowly stopped and there was a notable change in their physical appearance.

I was amazed at their transformation in physical appearance and they too were shocked at

⁶⁰ Beatrice, Leo, Innocent and Molly. But, as earlier noted, Beatrice died because she started the drugs at a late stage. So this section only focuses on the three that survived.

how good they looked. During the second-last visit to Innocent's home, Innocent and I talked a lot about ARVs and TB drugs - how effective they were and how they had changed his appearance. In fact, Innocent talked endlessly about how good he looked and felt. *"I was in a very bad state when I got here," he explained, "My relatives thought I was dead. I think even the taxi driver who brought me here will have a shock of his life when he sees me in Kitwe. He will think that he has seen a ghost. I remember how terrible I looked when you first saw me. But here I am very fit. I never thought that I would get well and look the way I am looking today. It is a miracle, the medicine has done wonders."*

He went on to explain how his counsellor from ZAMBART failed to recognise him. *"Do you know what happened the other day?" he eagerly asked and, without waiting for my reply, he continued to narrate what had happened, "I was standing under that tree and Mr. Chibola came to visit. He passed right here and greeted me then he continued walking towards my hut. I wondered what he was doing but I did not say anything instead I followed him thinking he wanted us to sit at our usual spot. When he reached my hut he checked around and then he turned and asked me where Innocent was? I laughed! I really laughed, but when he saw me laughing then he realised that he was actually talking to me. He asked, 'Is that you? Hey man you have gained weight and you look good!' He was shocked, after that incident I also realised that I had fully recovered and was ready to go back to Kitwe."*

Leo also recalled how his physical appearance before ARVs caused people to stare. *"The time my neck was swollen people used to be scared of me. Whenever I entered the bus everyone would look at me and some would move away from me but now I am happy my neck is no longer swollen. I used to feel uncomfortable because everywhere I went people used to stare at me. The nurses at Monze hospital told me that since I was on ARVs my neck would clear and I would be well but I did not believe them. But now I believe that I will be completely cured."*

When I first met some of the nine people at the time when they were diagnosed with TB and beginning TB treatment, I thought they were more worried about their lives and who

was going to look after their children if they died. But as I saw their excitement as their physical appearance started improving, I came to realise that physical appearance bothered them too; it was just that we never spoke about it as often.

In Innocent, Leo and Molly's life, transformation had taken place. Although they had not fully recovered, they were performing some activities that would bring in a bit of income. In July 2007, Leo went back to Mazabuka with the hope of starting his video and audio tape business once more. All he needed was capital. He was hoping that some of his friends would help him with a loan.

Similarly Innocent had gone back to Kitwe. I had called him in September 2007 to find out how he was getting on and if he had managed to find a clinic where he could access ARVs. *"I am fine,"* he said, *"though I feel very weak at times so I can only manage to work half day. I am lucky my boss is very understanding. The other problem is that I feel very itchy; maybe it is the effects of the medicine."* When I asked him about food he replied, *"Life is tough, with my half pay I cannot manage to eat what I would like because I have to send my son to school and also have to pay for rent."*

Like her brother, Molly had left home for Choma. She had gone to Choma to live with her sister with a hope of starting a business of making tablecloths.

Their parents, on the other hand, were worried about the debts that they had acquired during the illness episode. In addition to debts, both Leo and Molly's parents had run out of maize by June 2007. Leo's mother and Molly and Innocent's parents were hopeful that their debts would be paid off once their children started earning enough. *"We owe a lot of people money. Maybe when Innocent starts work he will send us some money to pay off the debts,"* Rachael said hopefully.

Surviving AIDS and TB for the three was not only a matter of curing the disease but also of surviving as a social person. During the illness episode all nine people were isolated from friends and some family members. In Leo's case, his wife left him at a time when he

needed her. *"I wish my wife were here to care for me because there are a few things that my mother cannot do. She is my mother so she has limits. A mother can only do so much but a wife can do everything for you - she can bath you and wash your underpants,"* Leo narrated at a point when he was very ill and needed assistance with bathing and eating.

Improved physical appearances in Leo's life also lead to a rekindled relationship between him and his wife. When Leo was fine and looking healthy due to ARVs, his wife came back. Towards the end of his TB treatment she had gone to visit him at his mother's house. When Leo met Florence (my research assistant) two months after we had completed field work Leo informed her that he was living with his wife and son in Mazabuka. Although he still complained about not having sufficient food for his family and himself.

Due to the transformation that came with ARVs, other relationships improved too. As can be seen in Chapter Five, all three had at one point quarrelled with their caregivers and the illness had caused a lot of stress on relationships; but when the patients were healthy and fully recovering, relationships rekindled. *"The illness has taught me a lot about my family. I have come to appreciate my mother and siblings. When you are doing fine in life everyone pretends to be your friend but when things are bad no one wants to be your friend,"* Leo explained.

A bond is not something that a researcher can measure, but through observations I was able to see the closeness that had developed between the three and their mothers as compared to the earlier conflicts. Molly no longer referred to her mother as a "demon" and before she moved to her sister's home in Choma, I saw that they seemed to get along fine.

In addition to family relationships, two were determined to transform some negative habits. Leo and Innocent were determined not to resume negative habits like drinking and smoking. *"I will never drink or smoke in my life!"* Leo exclaimed when asked if he had visited a bar now that he was well. Similarly Innocent said he would not drink but, unlike Leo, he thought it would be no problem to visit a bar. *"My friends would want to take me to the bar. I used to buy a lot of beer for my friend so they like me. So when they hear that I*

am back they will come to visit me. But maybe I will go to the bar but I will not drink with them. I will sit to chat but that will be all."

From the above we can see that Innocent, Leo and Molly's lives had transformed. They had hope for a better future since they were able to get back to productive activities. Their relationships had rekindled and they were determined to transform some negative habits. But there was a question on my mind: What was the cost of this transformation?

In Chapter Four, we established that accessing ART in the rural area involved repeated visits to the hospital and substantial costs. It was also established that all three that had managed to start ARVs had borrowed extensively to enable them meet all the costs. They also sold some of their valuable assets and many were paying off debts. By the time I ended my fieldwork the debts had not been paid off, none of the assets had been replaced and their food production had not been restored. This implies that the families of the three did not cope with the illness. According to Rugalema:

"To cope is to overcome a difficult situation so that, for example, after a disaster or other major setback, a household is able to regain its former living standard, or even surpass it. This implies that households and communities are able to rebuild their lives or to rebound from the nadir of the disaster. In other words, assets disposed of are recovered, food production restored, etc." (2000: 538)

Thus, the patients were transformed, but the families tipped. Innocent, Leo and Molly were able to go back to their original way of life while their parents who took care of them during the illness episode were left in debt and were food insecure (Chapter Four).

My second question is whether Innocent, Leo and Molly's transformation is sustainable, since all the three still complained about insufficient food?

"The medicine is too strong and it leaves me very weak. When I take the medicine on an empty stomach I usually have a black out. I had a black out last week. I tell you suffering from TB and taking ARVs but no food is torture," explained Leo.

Taking drugs on an empty stomach is perceived as dangerous, especially in the case of ARVs, which are very strong. My fieldwork revealed that people on ARVs could not afford to maintain the balanced diet they needed to compliment the drugs because all complained about insufficient food. All three had been advised by the clinic staff to maintain a balanced diet but unfortunately for them this was impossible because they had used almost all their money during treatment seeking.

“The nurse at the ARV clinic told me that I have lost a lot of weight. She advised me to eat more but the problem is that we do not have food at this home to make me gain weight. I am worried I might not gain the required weight,” Molly complained. She further explained that it was not possible for her to buy the foods that she was advised to eat. *“I was told to eat a lot of fruits, less cooking oil in my food, relish with groundnuts. In short, I am supposed to have a balanced diet, which includes carbohydrates and proteins. All the foodstuffs I have mentioned are expensive. We can only afford vegetables so I will never gain weight.”*

Months after the end of my fieldwork, as seen from above, the participants were still complaining about lack of food. The question is: Will they still continue to take the ARV drugs two years from now if their current food situations persist? Available literature states that adherence to ART and its efficacy are significantly influenced by access to adequate food and nutrition (Castleman et al. 2003; ODI briefing paper August 2006; Weiser et al. 2003). It is important to keep in mind that these are poor people that have become even poorer due to illness-related costs that lead them to sell livestock and to borrow heavily.

Literature from Singapore on ART patients reveals that those who start treatment while malnourished have significantly poorer survival, making them six times more likely to die than patients who receive adequate nutrition (Paton et al. 2006). Similarly, additional literature reveals that malnourished people are typically more vulnerable to parasitic and infectious diseases and their illnesses are more severe than those of well-nourished people (Edstrom et al. 2007; Gillespie and Kadiyala 2005; Scrimslaw and SanGiovanni 1997; WFP

2004b). Though Raiten (2006 cited in Friis 2006) argues that there is not yet enough available data to make conclusive statements, evidence is emerging that people on ART receiving food supplementation recover much faster (Edstrom et al. 2007; Sadler 2006).

Therefore people on ARVs need a good diet for them to live a happy healthy life. They need to feel that they are food secure. From the complaints of the three people who were privileged to start ARVs I would conclude that they were food insecure. The question on my mind is, if their food insecurity situation persists, will they live for many years? Will they continue with the medication or give up with the view that it is the cause of the hunger inside? I wonder how their lives will be two, three or four years from now. Yes, they did transform but to what extent is this transformation? Would their debts be paid off? Would their lives be as they were before? Could their household recover? If so, when will be that be? And to what extent? I am unable to answer these questions given that I only spent time with the families during the eight-month TB treatment period and not beyond. Therefore I would urge for more research to be conducted by anthropologists and other social scientists on the lives of poor people post ARVs. My assumption is that the families are far from recovering.

6.4 Living with HIV and not on ARVs

Two out of the nine participants were HIV positive but not on ARVs. Unlike Innocent, Leo and Molly; Rocky and Mukupa faced a more uncertain future. By the end of fieldwork, Mukupa was cured of TB but was still in denial about her HIV status. Denial was a negative element in Mukupa's life because the wall of silence hindered her from getting both the proper care that she needed and the proper information that health staff distribute on positive living. That way, she would be in a position to prevent other opportunistic infections that might come along. "If people are so afraid to acknowledge or even find out that they are infected, they will lose precious opportunities for warding off or treating illnesses brought on by the infection" (UNAIDS 2005:40). Thus, Mukupa's denial is not healthy for her and may put her in risky situations.

Rocky too was cured of TB although he still complained of body pains. On my visit in July 2006, Rocky complained of pain in his legs. When I asked if he was able to work he said, *"At the moment I am able to do some work at home though I am not so fit. I helped my wife harvest the little maize that we planted. Sometimes I herd the goats with the children."* Rocky could only manage to do a bit of housework and was not in a position to do more. By the end of my fieldwork Rocky was still unemployed and his family was struggling to find money. To make matters worse, his mother fell ill. Mary had suffered from herpes zoster twice during the eight months of Rocky's illness. Herpes zoster has come to suggest early HIV disease (Farmer 1999:3). On my last visit, Mary looked weak but was trying her best to appear strong for her son and grandchildren who always seem gloomy when she is unwell. Having known her for some time, I could tell that she was in a lot of pain. Mary's illness further reduced their source of income because she could not carry on the business of selling second-hand clothes. Rocky's wife became Mary's caregiver. It seems as if illness is far from leaving this family.

Due to lack of money, Rocky visited the ARV clinic once but had no funds for a second visit. Therefore, though willing to seek medical advice, he could not afford it. The repeated visits were too expensive for him. He had no more assets to sell and he could not borrow any money since the family had not repaid a single cent of the money they had already borrowed.

Despite this, Rocky narrated that his social network was slowly expanding. *"People are surprised to see me looking so fit. So many of them come to pass through and they say hello. My wife thinks that some of them are just coming here so that they can really see for themselves that I am now fine. Anyway, I do not mind if they come here because they want to gossip or they come here because they genuinely want to see me. I am just happy that I am fine."* I wonder if his social network will fully expand considering the fact that his mother is now ill.

From the above I can say that both Mukupa and Rocky face a more uncertain future. Mukupa's position of denial is a risk to her health and might cause her more harm in

future. Rocky and his family, on the other hand, have tipped and are likely to tip even further due to his mother's illness. Although his social network appears to be expanding, this might diminish once his mother deteriorates further. Secondly, he has not regained his economic activities and is still not fit to do so. His hope could have been ARVs but unfortunately, he is unable to afford these. My only hope for Mukupa and Rocky is that their lives do not tip to the extent that Alex and Beatrice's did.

6. 5 Exclusively TB

TB is a deadly disease but it becomes even worse when the person is suffering from both TB and HIV (Farmer 1999; WFP 2004a). Thus for Victor and Yvonne, who were suffering only from TB, the outcome was not as severe. By end of treatment, they had resumed work and their social life had improved.

Though Victor had lost most of his contracts as a builder, by the end of TB treatment he had slowly started to win them back. By the end of fieldwork, Victor was building once more and was rarely found at home. Though he and his wife had acquired some debts during his illness, they were hopeful that they would pay all of them because Victor was able to work once more. Victor had also resumed his social habits and was spending time at bars with his friends. Though he was not willing to disclose this, his wife told us her husband was drinking once more and she wished he would stop.

Victor regained self-esteem. He was happy that, at last, he could take care of his family once more. *"I am able to bring some money home but, like I said, I have lost most clients so the money that I am generating at the moment is not much. But I am happy because I can provide for them."*

Yvonne, too, was back to her old social life. Unlike the others, she never faced the same degree of isolation. By four months into treatment, Yvonne used to have many visits from friends and relatives. Some of her friends used to help her with relish. By the end of treatment, she was back to selling fruits and vegetables at the market.

In July 2007, Yvonne was unwell and could not continue with her business. She had suffered an epilepsy attack. According to Florence, who paid her a visit, Yvonne had attended a funeral at her neighbour's house and - upon seeing the dead body - she had had an attack. Yvonne's daughter explained that her mother's illness was on and off, and the family was still struggling as a result. At the last visit, we established that her disabled children were still not back in the special school. This family too had not yet paid back its debts.

I would say that tipping did not take place in Victor's case. In time, Victor and his family will get back to their normal life. Yvonne, on the other hand, is a special case. Her case demonstrates that TB in the context of vulnerabilities other than HIV can indeed tip a household. She still faces many problems because, apart from suffering from TB, she also suffers from epilepsy. In addition - as seen from the case study - four out of six of her children are disabled. Thus, she is not able to attain a "normal" life, and she is still worried about how she will pay for her children's fees so that they could get enrolled once more in the special school for the disabled. Secondly, her daughter cannot have the life that she dreams about - living with the father of her two children in Kalomo. Whilst in Kalomo Funny also hopes to start night school, but her dreams will probably never come to pass because she will always have to take care of her mother and her siblings. Maybe this dream could come to pass if there was more help from government and NGO/welfare institutions in Pemba/Batoka.

CHAPTER SEVEN

CONCLUSION

Do poor rural households have the capacity to cope with the trajectory of TB illness in the context of food insecurity and at this stage of the HIV epidemic without external welfare support? I asked this question in the introduction to this thesis. The experiences and stories of the nine participants seem to suggest they do not. Their stories and experiences reveal that the extended family may have been overstretched with the burden of TB and HIV. There was less support from the extended family and an absence of external material assistance from the state or NGOs. Although some received spiritual support from churches, and all were receiving a ZAMSTAR household counselling intervention, the care of TB patients largely fell on female kin.

Due to a lack of assistance, primary caregivers were often overstretched and exhausted, and ended up ill themselves. The patients and their family members faced not only physical but emotional problems. Children frequently had to take up the role of secondary caregiver, bathing and feeding parents. The families were emotionally drained by the end of TB treatment; in some households this signalled more long-term problems. Some families split because they could not manage the cost of illness and moved in with other relatives with the hope of having a better life. One family broke up due to stigma. The “burden” placed on family members is not always experienced in empathetic terms. Indeed, care - as a social category based on notions of altruism - may in times of stress be perceived as a burden with stigmatising consequences for the patient.

The experiences of the nine participants and their families also showed that TB can cause loss of production when farming is neglected at the expense of the patient. To have a better understanding of this, affected and non-affected households were compared. Due to illness, affected households reported a reduction in land use because fewer family members were available to work in the fields. Unlike non-affected households who spent most of the farming season in the field ploughing or planting, affected households were

usually at home. The fear of leaving the patient alone compelled most of the caregivers to stay close to the patient, but this in turn affected farming patterns such that, during harvest time, none of the affected households reported a drop in maize harvest while seven out of the eight affected households reported a drop in the maize harvest. A drop in maize harvest meant shortage of food sooner than expected – leading to more food insecurity.

Apart from emotional and food problems, the experiences of the nine patients also revealed that they were also economically drained as result of having to pay for transport to health centres, especially when repeated visits were required. Seven of the nine TB patients were living with HIV. Accessing ART in the rural area involved repeated visits to the hospital and substantial costs. An observation at the ART clinic 60kms from Pemba revealed that, on average, PLWH had to make more than four trips before commencing ART.

Apart from spending on medical costs, lost income was reported by all patients and reduced income by caregivers because it was difficult to ensure income-generating activities when taking care of the ill or accompanying them to RHC or hospitals. They also had to withdraw investments that they had made and often went into debt, while non-affected households seemed to be able to not only feed themselves in 2006/7 but, in some cases, increase their capital.

The study also revealed that two of the nine TB patients who were HIV negative were never as ill, and never faced the same degree of isolation, as the rest. By the end of treatment, they had resumed work and their old social lives, although one had had to withdraw her disabled children from a special school.

During the course of the study, two of the nine TB patients died (one never managed to get to the ARV clinic despite having an appointment; the other faced delays accessing transport money and died one month into treatment). The cost of the funeral (coffin, funeral, food) tipped the household into further debt and deeper poverty.

For three out of four who managed to start ARV there was hope. Their physical and

emotional transformation was especially striking. They experienced improved physical well-being, re-kindled relationships, expanded their social networks, resumed livelihoods and were determined not to continue negative social habits (e.g. heavy drinking).

Although we do not know if this transformation is sustainable over time (this would only be established by more research), I am certain that ARVs are effective. Therefore, further research is needed on the life of PLWH post ARVs. It can also help to establish what happens to the patient's food desires; and whether the rest of the household is able to get back to the life they had led before the patient fell ill. I believe this is an area in which anthropologists can make a significant contribution. In addition, more longitudinal studies need to be done on the widows and orphans after the death of a PLWH. These studies should give a detailed ethnographic account of the life conditions and experiences that widows and orphans go through.

Recommendations

Before the final recommendations, it is important that we first focus on the problems raised in chapter one. Who should take up the role of caring for the poor?

Improving service delivery to the poor involves all the major stakeholders in the health system - the policymakers in ministry of health, health service managers and health workers, NGOs and communities, families and individuals themselves.

To begin this journey NGOs must not work against each other but with each other. Firstly it is not ideal that a small village like Pemba/Pemba should have 14 institutions all working towards the management of TB and HIV in isolation when they are all fighting the same fight. The best is to put all their resources together, plan and map out a strategy of how best they can help the people as one. Together with government they can

- Renovate health centres – improve the infrastructure by providing necessary equipment such as laboratory facilities, enough room for all programs and activities

to run simultaneously without embarrassing the patients or subjecting them to uncomfortable situations.

- Train health staff in ART so that they are able to administer this service with little difficulties.
- Fund more health care workers and improve their wages and working conditions.
- Train community health workers such as home based care givers and TB supporters in administering TB drugs⁶¹ and then offer them incentives i.e. a bag of maize meal per month, a proper uniform so that they feel they have a real job were they are appreciated.
- Empower the local home-based caregivers and treatment supporters. This can be done by providing bicycles or any form of transport that will enable them to reach as many patients as possible so as to administer DOTS. This, in turn, will help to reduce medical costs on the part of the patient and the family. In addition, more training needs to be given regarding the importance of confidentiality among the home-based groups.
- After the staff and CHW have been trained, aim for mobile health services so that people in far villages are able to benefit from all health services that the clinic provides.

The above points will help to identify practical and precise policy interventions that will lead to available, accessible and good quality health services.

Other recommendations that I would like to put forward are as follows

⁶¹ This decentralisation has worked very well in many communities but community health workers tend to stop assisting at the health center once they see that they are not getting any incentives.

- Firstly, access to sufficient food should be incorporated into TB and HIV treatment. This food should be provided by government or NGOs through the local clinics. The benefits of food aid or food supplements are that there will be an increase in household food security and also an increase in money available for other needs. These benefits will in turn generate subsequent changes in individuals in terms of weight, treatment adherence, productive capacity, and ultimately improve their quality of life.
- Emotional and welfare support to poor rural households with TB patients is critical, particularly in the first few months of treatment and if the TB patient dies.
- TB/HIV stigma experiences are common and need to be addressed through anti-stigma education that reaches patients, families and the wider community.
- Household counselling of TB patients is an effective mechanism for providing information, emotional support and encouraging HIV testing.
- For co-infected patients, contact with ART services is critical for regaining well being and ongoing treatment support.
- For rural co-infected patients, transport money or support is critical for accessing ART and ongoing treatment support.

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APPENDICES

Appendix 1: Household Profile – Composition and Recruitment Dates

<i>Household – no, name, location</i>	<i>No of adults in house</i>	<i>Gender & Age of adults</i>	<i>No of children in house</i>	<i>Gender & Age of children</i>	<i>No of TB patients in house</i>	<i>Gender & Age of TB patients</i>	<i>No of PLWH in house</i>	<i>Gender & Age of PLWH</i>	<i>Recruitment date</i>	<i>Last visits</i>
1A – Katoba, Batoka	3	M: 30 F: 53,22	5	M: 4 F: 14,7,3,6mths	1	30 (M)	2	53(F), 30(M)	21/09/06	August
1B – Michelo, Batoka	7	M: 64, 25, 22, 19 F: 59, 24, 32	4	M: 6 F: 11, 4, 2	None	n/a	Unknown	n/a	10/10/06	August
2A – Malambo, Kasiya	6	M: 54, 28, 26, 21 F: 72, 33	2	M: 13, 1	1 – died 06/11/06	54 (M)	1 – died 06/11/06	54 (M)	20/10/06	August
2 B – Hachimba, Kasiya	9	M: 70, 26, 23, 17, 17, 15 F: 67, 29, 15	4	F: 7, 6, 5, 2	None	N/a	Unknown	N/a	10/11/06	August
3A – Hibajene, Muzoka	6	M: 70, 38,27 F: 57, 30,25	8	F: 11, 11,9,8,6,3 M: 10,8,	2	25 (F), 38 (M)	4	38(M), 30(F), 27(M), 25(F)	22/11/06	August
3B – problems to recruit, Satanism fears									Not	August
4A – Nachibanga, Muzoka	7	M: 25, 18, 18, 18, 15 F: 54, 27	2	M: 9 mths F: 13	1	25 (M)	1	25(M)	24/11/06	August
4B – Mukuni, Muzoka	5	F: 61, 46, 22, 20 M: 15	3	M: 13, 4 F: 5	None	N/a	Unknown	N/a	29/11/06	August

Household – no, name, location	No of adults in house	Gender & Age of adults	No of children in house	Gender & Age of children	No of TB patients in house	Gender & Age of TB patients	No of PLWH in house	Gender & Age of PLWH	Recruitme nt date	Last visits
5A – Mweemba, Pemba	3	M: 34 F: 32, 30	4	M: 14, 11 F: 4, 1	1	30 (F)	2	34(M), 30(F)	05/12/06	August
5B – Banji, Pemba	3	M: 45 F: 36, 15	5	M: 13, 6 mths F: 9, 6, 5	None	N/a	Unknown	N/a	19/12/06	August
6A – Habenzu, Pemba	6	M: 32 F: 63 ,70+, 35,29,21	5	M: 11, 4mths F: 4, 3	1	21 (F)	1	21(F)	11/12/06	August
6B – Mweete, Pemba	3	M: 75 F: 65,21	1	M: 3	None	N/a	Unknown	N/a	09/12/07	August
7A – Hachita, Batoka	5	M: 42, 41 , 18 F: 36, 15	4	M: 13, 4 F: 6, 1	1	41 (M)	N/a	None	13/12/06	August
7B – Hakalima, Batoka	5	M: 49 , 17 F: 42,19,15	4	M: 13,6,3 F: 11	None	N/a	Unknown	N/a	17/01/07	August
8A – Samonga, Muzoka	6	F: 55 ,36,29 M: 31,27,22	2	M: 12 F: 4	1	55(F)	N/a	None	11/01/07	August
8B – Kachimba, Muzoka	4	F: 67 ,31,17 M: 19	2	M: 11,4	None	N/a	Unknown	N/a	25/01/07	August

Notes:

- All names are pseudonyms
- Head of household's age is in bold
- Lighter shading is TB patient household
- Darker shading is the non-affected household (comparative)

Appendix 2: Findings - Focus Group Discussions

Local Definitions of Poverty

‘Green Mangoes’

In Pemba/Batoka, poverty is mostly about shortage of food – ‘*hunger*’. A metaphor that was used again and again to refer to current poverty was that of people eating green, unripe mangoes, as professed by the Pemba NHC, “*These days people eat small green, raw mangoes when they have no food unlike years back*”. Green mangoes signify current hunger – in the past, people would wait for fruit to ripen and then pick the fruit and eat it or sell it. But now they pick unripe fruit and eat it “*as a meal*” (sometimes boiling them) or try to ripen the fruit fast in sacks so they can sell it. It also signifies a lack of restraint and limited knowledge of wild fruits (people sometimes now go to pick wild fruits but no longer know how to prepare them, and can end up poisoning themselves).

There were various degrees of poverty in Pemba/Batoka identified in the group discussions⁶². The poorest households were identified as those with almost nothing – no relatives, no food, hardly any housing, forced to beg with their bowls. Very poor households are those with no livestock and a small piece of land, whose *butala* (food barn) is empty and survive mainly through working as casual farm labour (‘piecework’) for others. Only able to afford one meal a day, the children do not go to school and are more likely to die, clothes are torn, belongings (including pots and plates) are few, there is no soap, housing is poor (for example, the roof is falling off), the environment is dirty and they cannot afford to send a patient to hospital or buy a coffin for a funeral. One group said that poor people are usually referred to as dogs – *babwa* (“*they are treated like dogs*”).

⁶² Focus group discussions were conducted with elderly people on 01/09/06, Kasiya Neighbourhood health committee (NHC) on 09/09/06, Batoka NHC on 19/10/06 and Pemba NHC on 13/09/06 to assess food economy trends, asking about food availability, accessibility and affordability, income sources and changes in food economy over time, wellbeing and wealth ranking as well as food particular for people with TB.

and no-one respects them", Kasiya NHC). The presence of a small amount of livestock (chickens), a medium piece of land and school going children would indicate a poor household. Rich households are those with large houses with iron roofing sheets, a large piece of land and livestock (cattle and goats), who have the ability to buy farm implements and hire labour, and who have a salary or their own business (like a shop), are able to support others and are able to have three nutritious meals a day and snacks in-between meals. Just as poor people are looked down upon in this rhetoric, rich people are resented, considered greedy, selfish and exploitative.

Most groups were quick to point out that poverty was not new – *"it was there a long time ago and it is still here"*, one man from Kasiya explained. Seasonally, hunger is worse from October through to February or March, in the lead up to the rains and planting and during the rains when the crops are ripening. Selling off assets such as livestock, bicycles and beddings, and stealing, is more common during this period. Food is also less available to buy at this time of year, and women marketers leave their children selling in the markets whilst they work in the fields.

Asked what caused current food shortages, the groups listed drought, lack of fertiliser, poor soils, water shortages, drinking, laziness, poor planning, too many wives⁶³ and children, illness (especially chronic or a short illness) and death (especially the costs of funerals and property grabbing). Some people were seen as caught in a poverty trap – unable to buy seeds and/or fertiliser, unable to plant and grow their own food and dependent on piecework and other strategies to survive. Others were said to slide from wealth to poverty through chronic illness, animal diseases, careless spending, having too many girlfriends, too many dependents and *'juju wealth'* (using witchcraft to get rich). Losing wealth can lead to confusion and depression. When asked more specifically about change that comes about with illness, the groups explained that when you have a patient at home, *"you get disturbed and cannot work well"* (Pemba elders), and spend most of your time taking care of the patient instead of going to the fields, often having to sell property to

⁶³ The Tonga practice polygamy (see Colson 1958).

raise money for transport to the clinic or hospital. Sickness – either short or long term – during planting or of a breadwinner was experienced as particularly disruptive. According to the home-based caregivers, in some households, TB patients - like poor people – are resented and “*treated more like dogs...some are actually called dogs*”. In the context of poverty, stigmatising behaviour can be as much a reflection of limited options as a reflection of attitudes (Bond 2006). Information from the group discussions held to have a general idea about people in Pemba/Pemba and also to group the families visited into wealth categories of poverty.

During the discussions an exercise was done with all participants to establish activities through out the year and the types of foods eaten during the year (see table below). Below is a table that shows a seasonal calendar for most common food and income sources in Pemba/Pemba. All food and income acquisition in Pemba/Batoka revolve around seasons. The months November to January are the most difficult months in terms of household food security.

The table below shows a seasonal calendar for most common food and income sources in Pemba/Pemba.

Activity	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Rainfall												
Land preparation												
Planting maize												
Planting sweet potatoes												
Planting groundnuts												
Weeding												
Green maize consumption												
Pumpkin consumption												
Harvest groundnuts												
Build maize barns												
Dry harvest of most food crops												
Livestock sales peak in January and February due to school fees and in October to December due to lack of staple grain, maize.												
Buy farm inputs and household furniture												
Ceremonies (a lot of marriages during this period because people have money from sale of crops). Lwiindi ceremony is carried out in October every year. During this ceremony Tonga people express their thanks for their previous harvest. Other ceremonies are nkolola- a traditional ceremony for young girls who have reached puberty.												
Moulding bricks												
Hunting												
On-farm casual labour												
Wild fruits												

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